

Sexuality experienced by women of different generations and HIV positive

Sexualidade vivida por mulheres de diferentes gerações e soropositivas para o HIV

Sexualidad vivida por mujeres de diferentes generaciones VIH-positivas

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Suto CS, Coelho EA, Paiva MS, Porcino C, Barros AR, Cajuhi AS, et al. Sexuality experienced by women of different generations and HIV positive. Acta Paul Enferm. 2021;34:eAPE02734.

DOI

<http://dx.doi.org/10.37689/acta-ape/2021A002734>

**Keywords**

HIV; Population groups; Women; Sexuality

Descritores

HIV; Grupos populacionais; Mulheres; Sexualidade

Descriptores

Grupos de población; Mujeres; Sexualidad; VIH

Submitted

September 30, 2019

Accepted

March 23, 2021

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Abstract

Objective: To analyze women's social representations of different generations that live with HIV about their sexuality.

Methods: Qualitative research with theoretical and methodological framework based on Social Representations theory carried out in a specialized attention service, in Bahia state, northeast Brazilian region, with 39 women. We processed the interviews with the Iramuteq software, which generated the Correspondence Factorial Analysis and the Descending Hierarchical Classification.

Results: The representations revealed (im)possibilities that pervade the sexual and affective intimacy between middle-aged women, the search for new strategies to experience sexuality for women of 30-44 years; the reaffirmation of fear of older women in revealing the diagnosis; and, through all generations, the treatment maintenance as a demonstration of affection to the partner.

Conclusion: The generational cutout revealed distinct aspects of social representations about sexuality experience. We highlight the necessity of new studies about the theme.

Resumo

Objetivo: Analisar as representações sociais de mulheres de diferentes gerações e que vivem com HIV sobre sua sexualidade.

Métodos: Pesquisa de abordagem qualitativa, com referencial teórico-metodológico baseado na Teoria das Representações Sociais, desenvolvida em um serviço de atenção especializada, no Estado da Bahia, região Nordeste do Brasil, com 39 mulheres. As entrevistas foram processadas pelo software Iramuteq, o qual gerou a Análise Fatorial de Correspondência e Classificação Hierárquica Descendente.

Resultados: As representações revelaram (im)possibilidades que permeiam a intimidade afetivossexual entre as mulheres de meia-idade; a busca por novas estratégias para vivenciar a sexualidade para mulheres com idade de 30-44 anos; a reafirmação do medo das idosas em revelar o diagnóstico; e, perpassando todas as gerações, a manutenção do tratamento como demonstração de afeto ao parceiro.

Conclusão: O recorte geracional revelou aspectos distintos das representações sociais sobre a vivência da sexualidade. Ratifica-se a necessidade de novos estudos sobre a temática.

Resumen

Objetivo: Analizar las representaciones sociales de mujeres de diferentes generaciones que viven con el VIH sobre su sexualidad.

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Conflicting interests: none.

Métodos: Estudio de enfoque cualitativo, con marco referencial teórico-metodológico basado en la teoría de las representaciones sociales, llevado a cabo en un servicio de atención especializada en el estado de Bahía, región Nordeste de Brasil, con 39 mujeres. Las encuestas fueron procesadas por el software Iramuteq, que generó el análisis factorial de correspondencia y la clasificación jerárquica descendiente.

Resultados: Las representaciones revelan (im)posibilidades que se impregnan en la intimidad afectiva-sexual de las mujeres de mediana edad, en la búsqueda de nuevas estrategias para vivir la sexualidad en mujeres entre 30 y 44 años, en la reafirmación del miedo de las mujeres mayores a revelar el diagnóstico y en mantener el tratamiento como demostración de afecto al compañero, que abarca a todas las generaciones.

Conclusión: El recorte generacional reveló distintos aspectos de las representaciones sociales sobre la vivencia de la sexualidad. Se confirma la necesidad de nuevos estudios sobre esta temática.

Introduction

Sexuality as a complex phenomenon is constructed and incorporate multiple dimensions that, according to the social, cultural, and religious context, suffer variation and promote changes of conception and individual experiences. In contemporary societies, sexuality is settled in distinct and available cultural representations, including those proposed by Biomedicine, which reinforces the (cis)heteronormativity as a pattern to sexual practices.⁽¹⁾

Since its discovery, the Acquired immunodeficiency syndrome (AIDS) is strictly related to sexuality, is configured as a global phenomenon for causing damage of great intensity to the population, and unleashed, in society, the debate about the pertinent values to sexual liberty, moral and gender relations.⁽²⁾ The epidemic is dynamic and is related to the living conditions, gender, ethnic, and age groups of the affected population.⁽³⁾ The social vulnerability that borders this reality goes through issues related to the exercise of citizenship and human rights. In this aspect, people that live with the Human Immunodeficiency Virus (HIV) face a set of specific problems, among them prejudice and discrimination.⁽⁴⁾

The greater vulnerability of women to HIV infection raises complex issues that go from the “expected” sexual behavior to each gender, the social role of men and women to be fulfilled, to the power dynamic between genders.⁽³⁾ In that sense, women still have their sexual autonomy compromised, which maintains gender inequality and asymmetry of relations that potentialize and overlap vulnerabilities.

Consequently, reducing the feminization of aids “implies increasing and developing the debate about sexuality and the experienced dilem-

mas related to this issue in an open manner and without prejudice.”⁽⁵⁾ Because the smaller decision in affective and sexual relations and the myth of unstable relations is still configured as expanded risk situations to the HIV independently of age/generation.⁽⁶⁾

In Latin America, in recent years, there was a large development of social-anthropological analysis with a focus on generations that aimed to intercalate with gender and sexuality thematic. However, the studies are centered on themes related to older adults, generations, and male homosexuality.⁽⁷⁾ By recognizing this gap, we aimed through this study to understand the social representations of women to learn about the sexuality phenomenon.

In front of this perspective, this study is justified by the necessity of comprehending sexuality under women’s point of view, considering generation aspects, aiming the strengthening and maintenance of health service bounds. This aspect could provide recognition by professionals when considered that sexuality is a demand for care in health, given the specificities and the necessity of greater attention at the scope of National Health System (SUS).

The study aimed to analyze the social representation of women in different generations that live with HIV about their sexuality. This is a project from the thesis entitled: “Sexuality of women in different generations after the HIV diagnosis” associated with the Post Graduate Programme in Nurse and Health of the Universidade Federal da Bahia (UFBA).

Methods

Exploratory research, with a qualitative approach, based on the Social Representations Theory

(SRT) for using mental tools that operate individual experiences in varied contexts. Although we have accessed the representations through discourse, they are elucidated by the nexus that establishes with the social surrounding.⁽⁸⁾

Women that live with HIV participated in this study and were monitored by one of the Specialized Attention Service (SAE) from a large city in the Northeast region of the Bahia State, Brazil. The respective municipality is known as the biggest town in population of the state's countryside, the sixth-largest inland city, and with a population higher than eight Brazilian capital cities.

We used intentional sampling once they corresponded to the predefined criteria: people over 18 years old and under the antiretroviral treatment (ART). As exclusion criteria, we used: those who were under the use of medicine as a prophylactic measure for HIV's vertical transmission.

We invited the participants to integrate the research through the nurse team while they were waiting for professional care. The sample was composed of 39 women. We adopted the saturation criteria to finish the collection.⁽⁹⁾

The data generation was carried out with a social profile characterization form application and through a semi-structured interview. We collected the data in a private room of the institution in the period from September to November 2018, guided by a script with questions related to the experience of sexuality and its relation to the HIV diagnosis. We recorded the statements and fully transcribed them to the corpus construction and analysis. Aiming to preserve anonymity, we identified participants with the letter P followed by a chronological sequence of participation, age in years, and HIV diagnosis time.

In the data processing stage, we used Iramuteq (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires) which is a free software for content and lexicometry analysis.⁽¹⁰⁾ Hence, for the analysis, we defined the Descending Hierarchical Classification (DHC) that classifies texts according to their specific words. The respective software has organized the data in a dendrogram providing re-

sults that allowed the description of each one of the five types⁽¹¹⁾ and enabled the construction of four empirical categories.

Later, we organized the excerpts of lines extracted from the interviews identifying the central ideas in complementarity to the CHD findings and the contrast analysis of variables modalities through the Factorial Correspondence Analysis (CFA). In CFA, the first factor (F1) explains 34,9% of total inertia, the second factor (F2) explains 26,2% allowing the presentation of variables between generations.

This research was approved by the Research Ethics Committee from the Nursing School of UFBA (#2.776.570/2017).

Results

The age of the 39 participants of this study varied between 22-74 years old, mean age 43 years old. The average time of HIV diagnosis was nine years, and the majority supported themselves through their own work and/or depended on Illness Aid or the partner's income. Regarding the education level, 11 had completed middle school, 21 high school, and seven higher education. After lemmatization, the interviews composed the corpus that the software separated in 898 segments of text through the initial context units (ICU) with the exploitation of 91.65%. We adopted the CHD composed only by terms with $p \leq 0,0001$ on each one of the types. Based on the CHD, we analyzed the set of words present in each one of the types and its relation to the object of research to the denomination of the categories. We carried out the identification of central ideas for each category, as exposed in figure 1, substantiated in the SRT.

The types revealed that the material faced fragmentation, resulting on four thematic axes: the first relates desires/wishes (type 5); the second comprehends two types and relates them to new ways of living sexuality and the absence of self-care (types 2 and 3); the third encompasses family setting and the everyday relations (type 4); and the fourth points out to issues directly related to the health/treatment (type 1).

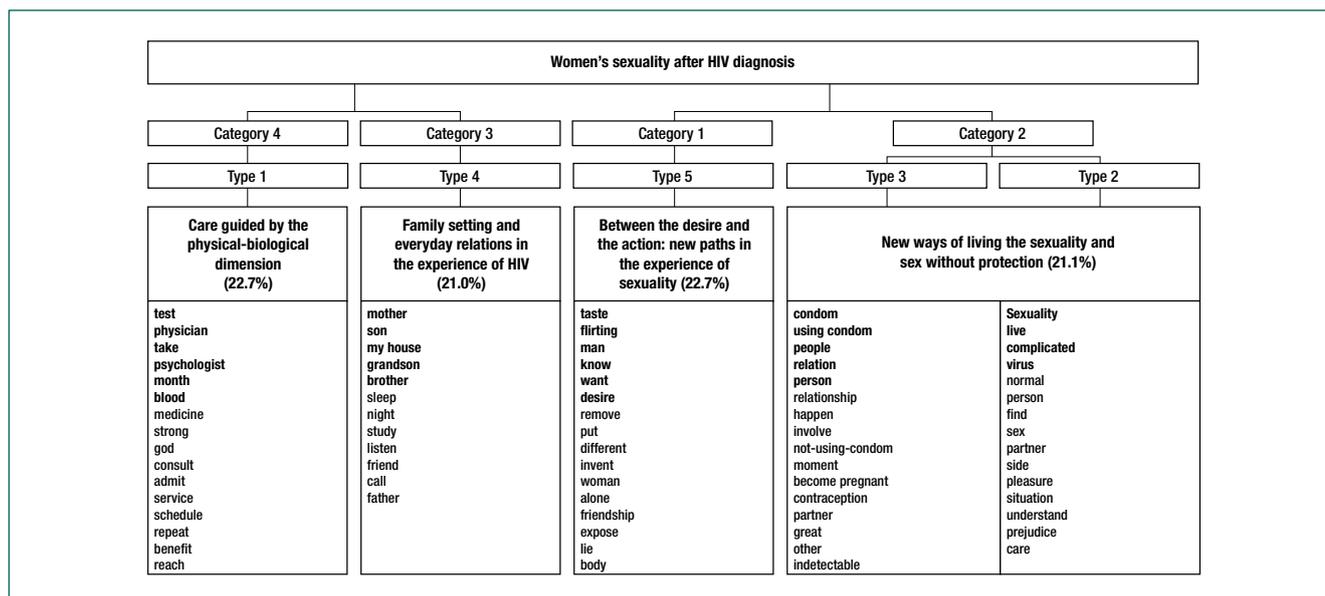


Figure 1. Thematic structure about women’s sexuality representation after the HIV diagnosis

Category 1– Between the desire and the action: new paths in sexuality experience

This category, composed of type 5, contains words that relate to daily desires and wishes of the experience of sexuality after the acknowledgment of the diagnosis. In the statements, the key-expressions were condensed in the core “like/want/will/man”. This organization was pointed out by the patients as an important support base of sexuality guided by the (cis)heteronormativity with (im)possibilities and/or perceived differences, highlighting the fragility that permeates the affective and sexual intimacy and the search for new strategies.

“For this flirt I’m something new but I no longer see him differently from me” (P 05, 56 years old, positive for 4y)

“This feeling of wanting or not a partner remains, at the beginning I didn’t” (P 13, 62 years, positive for 16y).

Category 2 - New ways of living the sexuality and sex without protection

The construction of this category encompasses types 2 and 3, in which the contents transcend the daily difficulties, prejudice confrontation, and the

impacts on the affective relationship, expanding them to the social context. The assigned score to the terms “using condom/not-using-condom/relation/virus/complicated” seems to express negligence regarding the self-care present in the sexual relations.

“Before the virus, we were really not used to thinking about ourselves.” (P 03, 26 years old, positive for 3y).

“I did not use condom, I did not think about pregnancy, I only found out later” (P 02, 33 years old, positive for 8y).

Category 3 - Family setting and everyday relations in the experience of HIV

The words belonging to this category, derived from type 4, were highlighted because of their personal and intimate character, once that the contents approached were the affective network and the family dynamic. The words “mother/son/grandson/brother” reaffirmed the importance of family interaction given the secret maintenance and the fear of revealing the diagnosis and their sexual practices.

“I suffered when I told my two boys [...] I was feeling very down” (P 20, 52 years old, positive for 16y).

“I feel kind of revolted because my family and my children were really outraged” (P 14, 69 years old, positive for 10y).

Category 4- Cuidado pautado na dimensão físico-biológica

This category incorporates the terms of type 1, pointing out changes and difficulties experienced by participants in the course of the diagnosis. Furthermore, it revealed aspects associated with the routine, especially those related to the exams and drug treatment. This axis moves away from the subjective and emotional contents relating itself to real objects of the HIV infection care/treatment.

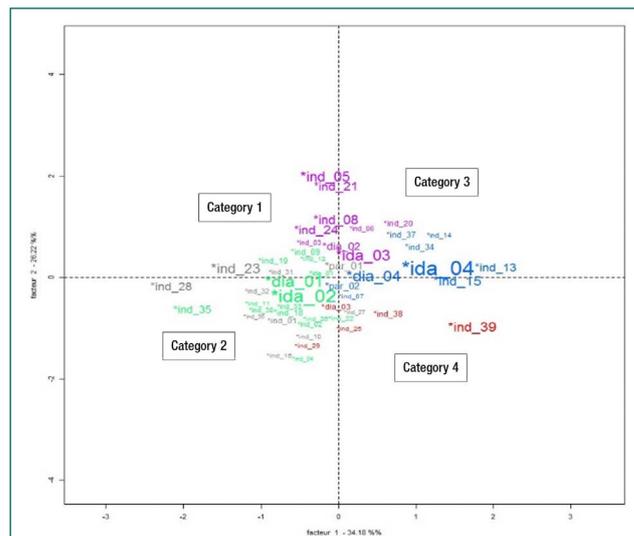
“We take care of one another [...] he reminds me that I have to take the medicine” (P 06, 22 years old, positive for 4y).

“It is hard, everything changes on a daily basis, there must be a time to take the medication.” (P 02, 33 years old, positive for 8y).

“Not missing the appointments, doing the exams, I am always around.” (P 27, 57 years old, positive for 12y).

“I did the exam because I flirt a lot” (P 15, 64 years old, positive for 30y).

As a possibility to show possible contrasts between the modalities of instituted variables in this study, for instance: person, age, time of diagnosis in the CFA (Figure 2), we used the vocabulary reduction in the following terms (“ind”, “ida”, and “dia”). The studied variables presented consonance with the composition of each one of the types in the DHC, and it exposes them distributing in quadrants. Hence, in the quadrants to the left are the contributions allocated in category 1, with a tendency of approximation in the ordinate Y; in the bottom left the category 2 assumes opposition to category 4, grouped more to the right; in direct opposition and assuming the centrality of the abscissa is the category 3.



dicating a distancing between what women desire and what they experience in sexuality, besides pointing out heteronormativity.

Female sexuality remains relevant in Brazilian society because it is conceived as a male control object transgressed by gender issues.⁽¹³⁾ That way, the most evoked words (Category 1) revealed issues from the affective and sexual life that may resonate in the affective, physical, psychic, and social dimensions of women and their partners. We observed that women around the age of 45-59 years old (middle age) were the group that contributed the most for this category conformation. In their testimony, we highlight that the presence of 'desire' and/or the 'denial of the desire' is associated with the fear of revealing their serological condition.

Therefore, despite all the movements in search of sexual liberty for women the modern discourse still sustains the repression of sexuality experience. Given that, insofar as the sex is talked about the repression connotes a certain transgression resolution.⁽¹⁴⁾ In that sense, the participants' testimony that composes category 1 sustained in the opposition between expressing the desire or denying it. The aspects reaffirm the experienced difficulties as if according to the positivity of HIV, the abstention for sexual practices were the rule for this generational group.

Women's oppression by men has emphasized the way of reproduction of sexuality experience, the sexual violence, and the women's human rights subtraction so that the difference between the sexes and genders would only no longer be structural as much as the exercise of power change. In that sense, feminism is an important tool that serves for the analysis of the political and cultural revolution changes, contradictions, limits, possibilities, and objectives initiated in the XIX century.⁽¹⁵⁾

We organized the second category, nominated "new ways of living the sexuality and sex without protection", in opposition to the previous one when we grouped participant's testimonies around the ages of 30-44 years old (Figure 2). For this generational group, the difficulties and prejudices experienced in the family scope and the affective and sexual relationships indicate an objectification of

sexuality in their representations of the terms "complicated" and "without a condom".

The reported experiences expose the asymmetries of relations and the difficulties faced in the preservative use negotiation as well as the partner resistance of use. This aspect may indicate the power/gender relation and in what circumstances the sexual practices occur without the preservative. Hence, in the experience of sexuality women encountered themselves without information about infection and perspectives of prevention that affects the quality of life directly. In their reports, adult women revealed that the knowledge of prevention/protection related to HIV before the beginning of the treatment practically did not exist.

The difficulty in prevention during sex conforms with the findings of research with young women that recognized the female preservative as a technology that provides autonomy and protects from Sexually Transmitted Infections (STI), however, they reported discomfort and strangeness.⁽¹⁶⁾ We highlight that the aids confrontation in Brazil and the handling of STI in the sexually active population is challenging considering the reduction of preservative use.⁽¹⁷⁾

Another aspect revealed in category 2 was the prejudice present mainly in affective and sexual intimacy. In that sense, a study with asymptomatic women around the age of 27 to 37 years old and followed in an SAE in Recife also evidenced stories marked by discrimination in everyday experience since the diagnosis occasioning the occultation of their serological condition.⁽¹⁸⁾

In our study, the third category entitled "Family setting and everyday relations in the experience of HIV" had as a characteristic the participation of women over the age of 60 years old (old). These women, when talking about sexuality, denoted aspects concerning the family relations through the words 'mother/son/grandson/brother'. Women, most of the time, are still seen as 'mother/young/wife', an aspect that restricts the inclusiveness of other possibilities and excludes women that do not fit this profile.

In the manifestation of aids, we observed multiple feelings or determinations given the

tendency to greater longevity of people that live with HIV.^(19,20) When addressing the effects of the aging process in the experience of sexuality and gender of subjects among the ages 52-82 years old, referred to as homosexual men, the authors observed that there is an “unstoppable relation between aging and sexuality” and analyzed a tendency of these subjects to transform themselves into “more discreet men.”⁽⁷⁾ Regarding the participants of this study (women), their social representation seems to reveal that such phenomenon is strongly identified.

Currently, in Brazil, the epidemic of aids is confronted with services of reference in assistance, technology for prevention, and treatment. However, its implementation on SUS still is low, mainly in the majority of Brazilian northeast interior cities. This reality indicates a gap that enables the visualization of the decentralization and integrality limits as difficulty factors for the access to the health services and the universality of SUS in the last 30 years.^(20,21)

Considering the fourth category of this study, which approaches the “Care guided by the physical-biological dimension”, its composition revealed elements of women’s discourse around the ages of 22-74 years old. The contents depict HIV therapeutic treatment and indicated that even when access is guaranteed, the discomfort of arriving and remaining at the SAE was embarrassing. Because this aspect may constitute itself in elements that enable the revelation of their condition (someone living with HIV) to the community.

In this category are present elements that denoted the modifications in the routine of HIV seropositive women, as much as they experience sexuality, once that the care with the disease became primordial. The participants’ reports elucidated that going to the health service, the examining, and the abandonment of sexual practices, not thought before, became a constant in their lives.

The studied categories with the generational cut-out revealed distinct aspects of the social representations about the experience of sexuality. Therefore, women between the ages of 30-59 years old revealed the subtlety between desire and the action in the

search for new paths for the experience of sexuality by developing strategies and avoiding sex without protection. For participants over the age of 60 years old the family context and the everyday relations overlap sexuality. However, independently of the age, the representation also goes through the care guided in the physical and biological dimension, as far as it pulls away from the emotional and subjective contents.

The Social Representations (SR) constitute themselves in dynamic processes that embrace subjective aspects, affections, and cognitions that influence the change of attitudes and/or someone’s practices in a given social context.⁽⁸⁾ Hence, on one hand, the experience of sexuality may carry beliefs and opinions built and shared by individuals and groups. On the other hand, it may result in the interpretation of the symbolic and social universe of the investigated group in their environment and/or social surroundings, as far as it provides the maintenance and/or resignification of the behaviors and social practices of women living with HIV.

Conclusion

Women’s social representation that lives with HIV about sexuality presented divergences between generations. It revealed (im)possibilities and/or fragilities that pervade the sexual and affective intimacy between middle-aged women; adult women searching for new strategies to experience sexuality; older women reaffirmed the fear of revealing the diagnosis and their sexual practices to partners/relatives. The daily care/treatment routine was a highlight in women’s life, independently of generation. In these circumstances, sexual representation pervades by occulting the willingness/desire and prioritizing the improvement of quality life and the established relationships that impact the support. The generational issues stood out by distinctly influencing the contribution and confirmation in the representative categories. We highlight, therefore, the necessity of new studies that approach this thematic and that privilege the generational category.

Acknowledgements

Financial support: Research Support Foundation of the State of Bahia, through the scholarship: BOL0396/2018.

Collaborations

Suto CSS, Coelho EAC, Paiva MS, Porcino C, Barros AR, Cajuhi AS and Silva DO collaborated with the conception of the study, analysis and data interpretation, writing of the article, critically revising and approving relevant intellectual content for the final version to be published.

References

1. David CM, Silva HM, Ribeiro R, Lemos SS. Desafios contemporâneos da educação. São Paulo: UNESP; 2015.
2. Calais LB, Jesus MA. Desvelando olhares: infância e AIDS nos discursos da sociedade. *Psicol Soc.* 2011;23(1):85-93.
3. Santos NJ. Mulher e negra: dupla vulnerabilidade às DST/HIV/aids. *Saúde Soc.* 2016;25(3):602-18.
4. Villela WV, Monteiro S. Gênero, estigma e saúde: reflexões a partir da prostituição, do aborto e do HIV/aids entre mulheres. *Epidemiol Serv Saúde.* 2017;24(3):531-40.
5. Conejeros I, Emig H, Ferrer L, Cabieses B, Ianelli R. Conocimientos, actitudes y percepciones de enfermeiros y estudiantes de enfermeira VIH/Sida. *Invest Educ Enferm.* 2010;28(3):345-54.
6. Carrara S. Moralidades, racionalidades e políticas sexuais no BRASIL contemporâneo. *Mana.* 2015;21(2):323-45.
7. Henning CE, Braz C, organizadores. Gênero, sexualidade e curso de vida: diálogos latino-americanos. Goiânia: Editora da Imprensa Universitária; 2017.
8. Moscovici S. Representações sociais: investigações em psicologia social. 5a ed. Petrópolis (RJ): Vozes; 2012.
9. Minayo MC. Pesquisa social: teoria, método e criatividade. Petrópolis (RJ): Vozes; 2016. 95p.
10. Camargo BV, Justo AM. Tutorial para uso do software IRAMUTEQ. França: Iramuteq; 2016 [cited 2021 Mar 12]. Available from: http://www.iramuteq.org/documentation/fichiers/Tutorial%20IRaMuTeQ%20em%20portugues_17.03.2016.pdf
11. Camargo BV, Justo AM. IRAMUTEQ: um software gratuito para análise de dados textuais. *Temas Psicol.* 2013;21(2):513-8.
12. Moraes DC, Oliveira RC, Prado AV, Cabral JR, Corrêa CA, Albuquerque MM. El conocimiento de las personas que viven con el VIH/SIDA acerca de la terapia antirretroviral. *Enferm Global.* 2018;49(1):111-26.
13. Parker R. Reflexões sobre a sexualidade na sociedade Latino-America: implicações para intervenções em face do HIV/AIDS. *Physis: Rev. Saúde Coletiva.* 1997;7(1):99-108.
14. Foucault M. História da sexualidade: a vontade de saber. Rio de Janeiro: Edições Graal; 2007. 178p.
15. Ferreira SL, Nascimento ER, Paiva MS. O pensamento feminista e os estudos de gênero: experiências na Escola de Enfermagem da UFBA. Salvador: EDUFBA/EIM; 2012. 156p.
16. Moraes AA, Suto CS, Oliveira EM, Paiva MS, Ferreira CS, Barreto MA. A look at female condoms from public school students. *Rev Gaúcha Enferm.* 2019;40:e20180277.
17. Streck VS. A feminização do HIV/AIDS: narrativas que interpelam as estruturas de poder na sociedade e igreja. *Estudos Teológicos.* 2012;52(2):345-56.
18. Renesto HM, Falbo AR, Souza E, Vasconcelos MG. Coping and perception of women with HIV infection. *Rev Saude Publica.* 2014;48(1):36-42.
19. Silva KG, Silva RP, Barbosa JM, Moura IS. Clinical-nutritional profile of HIV patients in a referral hospital in the northeast of Brazil. *J Bras Doenças Sex Transm.* 2016;28(2):50-5.
20. Rocha S, Vieira A, Lyra J. Silenciosa conveniência: mulheres e Aids. *Rev Bras Ciênc Política.* 2013;11(11):119-41.
21. Silva CL, Cubas MR, Silva LL, Cabral LP, Grden CR, Nichiata LY. Diagnósticos de enfermagem associados às necessidades humanas no enfrentamento do HIV. *Acta Paul Enferm.* 2019;32(1):18-26.