Sexual and emotional experiences of women with urinary incontinence secondary to HTLV

Vivência sexual e afetiva de mulheres com incontinência urinária secundária ao HTLV

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Abstract

Objective: To understand the sexuality experience of women with urinary incontinence secondary to human T-cell lymphotropic virus (HTLV).

Methods: Qualitative study using oral thematic history and data collection through in-depth interview and, for analysis, the content and gender analysis technique.

Results: Ten women participated and four categories emerged: understanding sexuality; experiencing conflict and violence; experiencing sexuality without pleasure; and experiencing urinary losses during intercourse. Knowledge about sexuality and exercise was limited. Living with incontinence and the virus contributed to conflicts in marital and emotional relationships, surrounded by renunciation, limitation, gender-based violence, as well as life changes and adaptations to learning how to live with the disease.

Conclusion: Women had difficulty in performing their sexuality, and needed to change their lifestyle and empower themselves to live better.

Resumo

Objetivo: Apreender a vivência da sexualidade das mulheres com incontinência urinária secundária ao vírus linfotrópico de célula T humana (HTLV).

Métodos: Pesquisa qualitativa, utilizando-se história oral temática e coleta de dados por meio da entrevista em profundidade e para análise, a técnica de análise de conteúdo e gênero.

Resultados: Participaram dez mulheres e emergiram quatro categorias: Compreensão da sexualidade; Vivenciando conflitos e violência; Vivenciando a sexualidade desprovida de prazer; Vivenciando as perdas urinárias na sexualidade. O conhecimento sobre sexualidade e seu exercício foram limitados. Viver com a incontinência e o vírus contribuiu para uma relação conjugal e afetiva conflitantes, cercada de renúncias, limitações, violências de gênero, além de modificações e adaptações na vida, para aprender a conviver com a doença.

Conclusão: As mulheres apresentaram dificuldade em exercer a sexualidade, e precisaram modificar seus estilos de vida e se empoderarem para viver melhor.

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Introduction

The word "sexuality" refers to multiple meanings and interpretations. Initially it is related to sex, intercourse, and reproduction; however, there is the involvement of the whole body associated with the five senses, the symbolic attributes, and the human capacity to imagine and fantasize.[1]

The construction of sexuality involves social and cultural beliefs and ideologies.[2] In a broader dimension, this experience can be altered by the presence of a deficiency and/or a disease. Then there is a bigger issue regarding sexual performance, which is influenced by prejudice, stigma, body changes, and the fear of transmission.[3,4]

Among the sexually transmitted infections, we approached the human T-cell lymphotropic virus (HTLV). The most prevalent is type I, which is associated with the presence of adult T-cell leukemia/lymphoma and with HTLV-associated myelopathy/tropical spastic neurological paraparesis disease that causes muscle and neuromotor symptoms.[5] Neurological changes can compromise bladder performance, leading to a neurogenesis state, which causes urinary disorders such as nocturia, urgency, dysuria, hesitation and effort to urinate, the feeling that bladder-emptying is incomplete, and urinary incontinence.[5,6]

HTLV seropositivity is more pronounced in women than in men and increases after the age 40. The most probable explanation for this difference is sexual transmission, which is more efficient from men to women, and blood transfusions, which is more frequent in women.[6]

During the service, it was clear that this vulnerability influenced affective relationships, and to what extent it damaged sexuality. During the rehabilitation sessions, a high expectation of solving the complications arising from HTLV was evident, in terms of having the hope of again having a sexual life without any interference from urinary incontinence.

Women with incontinence secondary to HTLV differ from others who have other types of incontinence once they present, in addition to urinary symptoms, other myelopathy derivatives, such as perineal hypersensitivity, vaginal palpation pain, and hypertonia of pelvic floor muscle. These are added to neuromotor changes that impair their autonomy and mobility, such as march changes, patellar hyperreflexia, and lower limb hypertonia that affect daily activities, including sexuality, self-care, sleep, and willingness,[5,6] which constitute an aggravation of sexual performance.

Thus, the motivation for this study came from the clinical care experience of one of the authors of the study, who realized that women often expressed their dissatisfaction about changes in their sexuality following the urinary incontinence caused by HTLV. This question led the authors to enquire: How do women with urinary incontinence secondary to HTLV experience sexuality? Moreover, how does the gender relationship develop? To answer these questions, we defined the objective of understanding the sexual experiencing of women with urinary incontinence secondary to HTLV.

The importance of this study is emphasized as it explores the experiences of a specific group of women whose illness is poorly studied, and the obscurity of the problems experienced by them implies the quality of provided care. This study contributes to nursing professionals' understanding of how these women experience sexuality, given the limitations imposed by the incontinence and the virus, and support the planning of a specialized care. However, we do not intend to establish a generalization about sexuality, but rather to initiate a discussion based on the interpretations of narratives from women that live in a society with little clarification on this issue.

Methods

This is a qualitative study developed with patients addressed by services of the Bahia State to a public hospital with a specialized unit for infectious disease, in Salvador (Bahia) that cares for adults with HTLV.

The subjects were women who met the following inclusion criteria: adult; registered in the specialized service of infectious diseases; with confirmed HTLV diagnosis; presenting urinary incontinence; and able to answer the interview questions.

The subjects' participation was voluntary, free, and spontaneous, and their identities were preserved. There was no disruption to the care provided to the patients during data collection, and they were advised that they could cease their participation at any time, even after they had signed the Consent Form.

The approach to the participants was in the ambulatory. In a preliminary talk, they were invited to participate in the investigation. This kind of screening was used because frequently the information about urinary incontinence or other urinary abnormalities was not described in medical records.

For empirical data, we used oral thematic history, which put the discussion around a defined central issue, that being the narrative of a fact that was part of a whole life context, enabling participants to tell their history according to the way it is lived and experienced.[7,8]

The collection of testimonies was done through in-depth interview, which is recommended when access to the perceptions and behaviors is required, once it allows those interviewed to talk about their experiences, complaints, and concerns.[7,8] Associated with this, a semi-structured script served as the interviewers' guide, and the interviewers did not limit the patients to the narrated histories.

The interviews, recorded on a digital recorder, were completely transcribed later.

For data analysis, the collected narratives were submitted to the content and gender analysis technique, as an analytical tool for the content related to women's issues in the face of the men; on their role in the society, in the private media, in family and in public; how they saw themselves; and how they behaved according to their principles, values, beliefs and social norms.

The study follows the 196/96 determinations and has no ethical repairs its approval.

Results

We interviewed 10 women with a mean age of 46 years (from 23 to 70 years) and a mean time of six years after a virus-positive diagnosis. However, even before the disease diagnosis, they already had neurological symptoms resulted from virus infection. One woman presented with congenital HTLV; another one had a yet-unconfirmed diagnosis, and the remaining eight patients had acquired the virus through sexual intercourse. Eight of them self-reported as black race, Catholic, with elementary education, and with an income of one minimum salary on average. They lived in 10 different cities in the Bahia State.

Regarding marital relations, five women said they currently had a good marital relationship and remained married; the other five were divorced after they were discovered to be contaminated by the virus, after the symptoms emerged, and after suffering physical, emotional, and psychological violence from their consorts.

Sexuality comprehension

During the nursing appointment, the interviewers asked what the interviewed women understood about sexuality and the answers were usually preceded by a moment of reflection and apparent difficulty in explaining something they either had no rule about or something they had no preconception about. In addition to modesty and shame, there was also a lack of knowledge on the issue. Some women reported a limited understanding of urinary incontinence as a binary relationship and necessarily linked to sexual intercourse and penetration. Only one interviewed woman, who had a higher level of education, described the concept of sexuality as something that involved not just sexual intercourse, but sensuality, pleasure without necessarily penetration, and not just done between a woman and a man, but also by people of the same sex or even

alone. She reported sexuality as the way someone dressed, felt, saw him/herself, and felt alive.

Experiencing changes in sexual behavior after HTLV diagnosis

There was low sexual interest. The lack of respect in the relationships associated with the consorts' betrayal, with the transmission of HTLV viruses, with situations of domestic violence, and with the disappointment over their consorts, contributed to the discredit of the affective relationships and the male figure, discouraging women from investing in their existing relationships or in a new one. In addition to the emotional and psychological disturbances, there were also physical and anatomical changes of the vagina and vaginal canal due to neuropathy caused by the virus and, in some women, caused also by menopause.

Another condition that contributed to decreasing sexual interest was the fear of virus transmission to the uninfected partner. There was the women's sense of altruism and respect in the face of their consort, a kind of feeling these women have not experienced with a partner that betrayed them.

Experiencing conflicts and violence

It was observed that men exerted power, hierarchy, and domination over the woman, who remained passive to male desires and to their psychological, emotional, and physical violent acts, in that it was common to have sex without the women's consent. The constant use of alcohol by some consorts also contributed to strengthen the aggressiveness of their violent acts and to keep women's feeling fear. However, the women that had suffered from this were able to empower themselves and become free from these violent relationships, choosing to remain alone.

Experiencing sexuality without pleasure

Women who remained married and had a good marital relationship reported that most of the time they had sex without pleasure, as if it was a wife's obligation just to satisfy her consort, and they rarely reached orgasm. They credited the lack of libido to the HTLV, the incontinence, and the pain they commonly felt in their bodies and during sexual penetration.

Experiencing urinary losses in sexuality

The urine loss, the moisture in the clothes, the unpleasant odor and the constant need to use absorbent denounced the inability of these women to control themselves, especially in a such private and personal moment as courtship, the moment of caresses, the touch time, and the penetration. The bladder catheterization relief procedure has also been reported as something that discouraged their sexuality, but at other times, it was a support to maintain continence. Women's positions for sexual intercourse were also expressed as a limiting factor, because they were afraid of losing urine depending on the effort they made, and the act of penetration sometimes contributed to a full bladder feeling and the urgency to urinate.

Due to incontinence, some women had low self-esteem, had lost their confidence in themselves, and therefore refused sexual relations. In addition, they showed an inability to establish a marital relationship.

Discussion

Understanding, through in-depth interview, the sexuality experiences of HTLV-positive women with urinary incontinence was satisfactory to learn about the reflections on the issue. There is a limitation on the number of women interviewed, but there was a convergence regarding the talks, with a great deal of information on the study's purposes and the construction of a matrix of analysis from the narrated stories with well-structured meaning cores.

It is known that the dialogue about sexuality may be embarrassing, and decency prevents free thought without prejudice. In addition, the lack of knowledge on the issue also contributes to reductionist definitions, because sexuality is pleasure in doing anything, such as to be at the side of someone, talking, touching, living.[5]

Vaginal changes such as atrophy, lack of lubrication, and dyspareunia arising from HTLV and from changes in hormone levels contribute to decrease the frequency and even suspend sexual relations,[9] mainly when restricted to penetration, limiting the possibilities of female pleasure.

The psycho-emotional changes such as feelings, interpersonal relationships, and self-esteem greatly influence sexuality. All of these things are interconnected, and it becomes worse when the woman has a disease, in terms of domestic violence and low self-esteem.[9,10]

In sexually transmitted diseases with little information, such as HTLV, the fear of viral transmission is real. The lack of discussion on the issue is an aggravating factor that moves the consort away and frightens people who have the virus with the fear of transmitting it, restraining new affective relationships. Additionally, after suffering violence, abandonment, and discrimination, loneliness becomes a woman's haven. Once she realizes all she has suffered, being alone may be her best option.[11,12]

Regarding this psychological aspect, the lack of libido and sexual denial could be managed in order to seek other alternatives for pleasure and personal satisfaction, reducing women's complaints and denials. Sensuality, the vanity, the care of her own body, the woman's relationship with her illness, the search for appreciation for herself and her body appearance, empowerment in the face of the consort and the construction of a balanced gender relation are socio-cultural elements for the performance of sexuality.[13,14]

Regarding gender analysis, sexuality, seen as a biological and instinctive impulse, is found mainly in men's talk, justifying the domination and sex impulse.[14,15] The idea that male sexual desire is uncontrollable, and that men have a "biological" need to having sex, makes women suffer even more at the time to perform "their role as wives," even if they are sick and with no desire.

This concept contributes greatly to women's passiveness in the face of male desires. In this way, gender identity reflects the active and virile behavior of men, and the passive behavior of women who do not have the feeling belonging to their own bodies, and consequently they are violated in favor of their partner's wishes.[15]

The male power, represented by physical and psychological strength and sexual desires, imposes an unequal emotional relationship in which gender issues are not worked through in order to balance the mutual interests between men and women.[16,17] Conversely, there is an oppressor just because there is an oppressed one.[16] Then it is essential for women to empower themselves in their relationships and decide what is best for them.

Given this social and emotional context, there is also an impact of the incontinence in these women's lives. The smell, the fear of getting wet in public, the need for catheterization, and the lack of control over their own bodies leads them to feelings of weakness, low self-esteem, social isolation, sexual repression, and a shortened sexual life.[18-20] Thus, it is believed that if health professionals, once meeting these women with the virus, have a more cautious view of incontinence symptoms and implement management techniques, these would not be experiencing incontinence associated with odor and shame.[18-20]

Implementing strategies to prevent incontinence, such as behavioral therapy, the use of products for urine restraint instead of using cloths, doing exercises for pelvic strengthening, knowing urination habits and, in some cases, using electrical stimulation and doing biofeedback with a specialized nurse, may considerably change the way women live and get along with their own sexuality.

Conclusion

Women who have the HTLV virus and urinary incontinence develop several social-affective and emotional conflicts, which hamper the performance of sexuality, resulting in losses to their satisfaction. However, when they empower and place themselves in the face of difficulties, these women can have a freer and happier life.

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Collaborations

Paranhos RFB, Paiva MS and Carvalho ESS state that they contributed to the study design, analysis and data interpretation, manuscript writing, relevant critical review of the intellectual content, and approval of the final version of this manuscript.

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