

The suffering of women living with HIV and inner love as a revolutionary practice

O sofrimento de mulheres que vivem com HIV e o amor interior como prática revolucionária

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ABSTRACT The study aims to discuss the suffering in the narratives of women living with HIV and the social obstacles that place them in underprivileged places. This descriptive, qualitative and exploratory research was based on the survey of narratives from participant members of the mental health group focused on women living with HIV. The data were analyzed through pre-analysis, material exploration, and data processing in light of the feminist authors Federici and hooks. The following categories of data analysis emerged from the women's narratives: the affective and social helplessness experienced after the HIV diagnosis and impotence and dispossession of one's own body in the face of seropositivity. The study showed the effects of the stigma associated with HIV and the resulting suffering. Based on the concepts of loneliness and love, we could reflect on the need for health professionals' care to consider biological aspects and listen to the suffering of seropositive women.

KEYWORDS Psychological distress. Loneliness. Love. HIV seropositivity. Comprehensive health care.

RESUMO O estudo teve como objetivo discutir sobre os sofrimentos presentes nas narrativas de mulheres que vivem com HIV e os entraves sociais que as colocam em lugares desprivilegiados em suas existências. Trata-se de pesquisa descritiva, exploratória, com abordagem qualitativa a partir do levantamento de narrativas de participantes integrantes do grupo de saúde mental voltado para mulheres que vivem com HIV. Os dados foram analisados percorrendo as fases de pré-análise, exploração do material e tratamento dos dados à luz das autoras feministas Federici e hooks. A partir das narrativas das mulheres, emergiram as seguintes categorias de análise dos dados: o desamparo afetivo e social experimentado após o diagnóstico do HIV; e o sentimento de impotência e de desapropriação do próprio corpo diante da soropositividade. O estudo mostrou os efeitos do estigma associado ao HIV e os sofrimentos que deles decorrem. A partir dos conceitos de solidão e amor, foi possível refletir sobre a necessidade de o cuidado dos profissionais de saúde considerar, além dos aspectos biológicos, a escuta do sofrimento vivido por mulheres com diagnóstico positivo para HIV.

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Introduction

This study assumes that inner love heals. This assertion is more than a word game. It is about the ethics of existence and resistance supported by feminist thinkers bell hooks and Silvia Federici. The concept of love here is by author bell hooks, pseudonym of Gloria Jean Watkins, in honor of her grandmother and officially spelled in lowercase to focus on the content of the writing and not necessarily on her identity.

However, what does inner love have to do with women living with the Human Immunodeficiency Virus (HIV)? Why does it heal? Would it be a paradox to link love (considered a happy affection) to the diagnosis of HIV (diagnosis with a sad affection)? Indeed, talking about love is a challenging issue in health, as we are used to studies that cover the theme of Sexually Transmitted Infections (STIs) from the perspective of symptoms, aggravations, and the epidemiology of an incurable disease. In other words, a biological perspective. However, this study employs the notion of cure proposed by bell hooks¹⁽¹²⁾, which moves away from a purely physical body illness logic.

When we know love, when we love, we can see the past differently; we can transform the present and dream the future. That's the power of love. Love heals.

Although the biological aspects of HIV infection are relevant in conducting therapeutic care for these women, this study aims to adopt in health care hooks' concept of inner love to think of more potent ways of caring for these women living with HIV. From this same perspective, the study proposes Federici's concept of loneliness to analyze the consequences on the mental health of women facing a diagnosis that affects their lives so harshly. Therefore, inner love assumes a concept of healing as far as the therapeutic care of health

professionals can promote spaces for sensitive listening and provide these women with opportunities to rethink the social barriers that place them in disadvantaged places for the simple fact of being women and less as a matter of biological HIV infection.

From the perspective of health care, we should consider the epidemiological and biological impact of this disease and, above all, the repercussions on women's life entirely, since the disease involves the environment, income, working conditions, housing, and leisure. Also, in this vein, one cannot neglect that HIV infection can lead them to experience many situations as life adjusts to the diagnosis, namely, the exclusion and disruption of affective and social relationships due to stigma and prejudice.

As far as women are concerned, discrimination in work relationships and domestic responsibilities exacerbates the problem. While women live longer than men and are more frequent users of health services, studies show that they get sick more often, and social discrimination is the primary producer of vulnerabilities². All of this can cause suffering and harm the quality of life.

Therefore, suffering escalates in women's bodies, which permeate several discourses, classifications, and regimes of hegemonic truths of patriarchal society. For Scott³, women's bodies are the territory most affected within gender inequalities, where social hierarchies and their stereotyped effects of the subordinate role to which women are submitted can be more clearly evidenced.

However, these aspects are hardly considered in health since the vision of women's care still prevails as something limited to care for a merely reproductive body. In this problem faced by health workers, an essential reference for (re)thinking care is precisely the possibility of considering that women's health is not confined to breasts, cervix, pregnancy, cancer, and STIs.

We invited theoretical references bell hooks, representative of the Black feminist

movement in the United States, and Italian philosopher, feminist activist, and co-founder of the International Feminist Collective Silvia Federici, to think about the challenges faced by women living with HIV. The following question emerges considering the above: how are the concepts of inner love and loneliness applied in healthcare to the suffering of women living with HIV?

This study aims to discuss the suffering of women living with HIV and the social barriers that place them in underprivileged places based on the concepts of loneliness and inner love in Federici and hooks.

Material and methods

This descriptive, qualitative, and exploratory study was elaborated following the recommendation of the Consolidated Criteria for Reporting Qualitative Research (COREQ)⁴. The study setting was a mental health group of women living with HIV proposed by professors at the Aurora de Afonso Costa Nursing School at the Fluminense Federal University (EEAAC/UFF) and meetings occur every fortnight with a duration of one and a half hours, in a virtual environment on the Google Meet platform, a video call tool that employs UFF's Gsuite, used during the COVID-19 pandemic. It is noteworthy that the recruitment for the formation of the mental health group was carried out on social networks through the COVID and HIV Campaign carried out by the Movimento Nacional das Cidadãs PositHIVas (National Movement of Seropositive Female Citizens, MNCP).

We established the following inclusion criteria: women over 18 and members of the mental health group aimed at people living with HIV. No exclusion criteria were applied, and all women who attended the group were invited by telephone. Thus, the researchers adopted purposeful sampling to select the study population, and eight women participated.

Data were collected from October 2020 to October 2021 by transcribing the narratives of the study components during the virtual meetings recorded with the participants' official authorization. Names of Greek goddesses were used as codenames to preserve the members' identities.

We built two thematic categories grounded on the content of the participants' narratives, namely: loneliness as affective and social helplessness experienced after the HIV diagnosis; and impotence and dispossession of one's own body in the face of seropositivity. The data were grouped by recurrent statements, traversing pre-analysis and material exploration stages as per Minayo⁵. Data were discussed in light of authors Federici and hooks.

This research complied with the National Health Council Resolution Nº 466/2012 which addresses the ethical principles of human research. Data was collected after approval by the Research Ethics Committee of the São Francisco de Assis Health Care Institute/Federal University of Rio de Janeiro (CEP/HESFA/UFRJ) under Opinion Nº 4.292.759 in September 2020.

Results

Eight participants living with HIV were part of the research, seven Black women and one white, aged 37-56. It is noteworthy that all are mothers, three reside in the Northeast, and five are from the Southeast. One is married and only three are in the labor market.

Loneliness as affective and social helplessness experienced after the HIV diagnosis

Regarding affective and social helplessness experienced by women after the HIV diagnosis, the participants' statements clearly evidence that they had greater social inclusion before being diagnosed with the disease, as can be seen in Afrodite's testimonies:

Before HIV, I was always the first guest at parties because I was the ultimate fun. I never went back to these events after I acquired HIV.

Atena also narrated that:

Here in my city, everyone knows [about HIV] and they are really prejudiced. I used to get work. Now I can't find a job... It's extremely hard.

It is evident from the reports that helplessness is also expressed in the lack of financial support from family and friends. Living with HIV can represent a high economic and social cost in these women's lives. For example, Deméter said:

I made my move all by myself. I had many expenses. Although the government donated the house and my family doesn't understand, it doesn't help. I almost starved last month because of this.

In this context, Hera reported: "*I fight a lot with my son because of money. I even feel bad because of it... I eat poorly because I don't have money...*".

We should emphasize that feeling alone was a perception found in the participants' narratives and the lack of support networks and solidarity. This 'walking alone in life' was demonstrated in the following statements: "*I was never loved and never loved*" (Athena); "*I'm too insecure to do things at home and go out alone*" (Héstia). In the same direction, Gaia spoke:

I've never been one to carry a cell phone. Now I've got a little bag to put around my neck carrying the cell phone because if I get sick when I'm alone, I have the cell phone to ask for help.

Eos said:

I think, 'if I fall ill, who will help me?'. Nobody. Nobody cares about me [crying]. I'll die in bed if I get an opportunistic disease.

The feeling of being exploited and having to do household chores was also expressed by women. Reports reveal that the participants, while feeling unsupported, also feel discredited in family relationships, as can be shown in the following statements:

For a few years, I have felt like this: the housecleaner, you know? I only serve to do this job. Everything I say is wrong. My daughter and grandchildren think everything I do to help is wrong. (Gaia).

The feeling also appears in another statement, as can be seen in Eos' speech:

It's hard for me to go to the health center to fix this dressing because I'm with all the children [grandchildren] here, you know... I always have to take one or two grandchildren with me to go to the doctor now, right?

The same feeling was described by Deméter when she said:

I no longer want to live in this situation with him [son] using drugs and fighting at home. Not anymore. I want to live the rest of my life. Because they have no idea... they don't care how much trouble I have. So, they don't even care. (Deméter).

Impotence and dispossession of one's own body in the face of seropositivity

In family relationships, the participants report a lack of support and disinvestment in what they can do and build in life. They display sadness and incapacity, as described in Deméter's accounts: "*Because of our health problems, we become so fragile... and we don't see our capacity*", which is also reported by Gaia:

If I say: 'Hey, I'm broke... I'm going to sell a crochet or a painting...', then they [family members] start saying: 'This is not going to work'.

In another statement, Gaia report:

I signed up for a free Spanish course here. Then I thought, 'Wow, that's crazy. What am I doing here?'. [...] my daughters said: 'Oh, mother, why are you doing this? You are way passed the study age'.

Afrodite narrates feelings of helplessness:

Because I was never happy again after I acquired HIV. However, I wanted to be happy again and smile as I used to before I was betrayed [marital betrayal responsible for the STI]. I want to see if I can be happy again next year and enjoy life more.

It is also noteworthy that women experience the feeling of dispossession of their bodies; in other words, a movement of self-depreciation and disintegration of their bodies vis-à-vis their nature, as shown in Atena's statement:

My son-in-law didn't like that I kissed his son, my grandson... He thinks I can't kiss and hug a child because I have HIV. As if I were dirty... It wasn't like that before.

Perséfone shows in her narrative the feeling of disintegration of her body after HIV when she says:

I was a pretty 'mulatto' with a beautiful body! Because of HIV, I am now without a single curve on my body: it's horrible. I looked like an old woman, all wrinkled. I have no flesh on my face or body.

One's body erasure after discovering HIV is found in Gaia's statement when she mentions: "*My body disappeared after HIV and medication. I'm a wreck. It's horrible!*" Héstia described a similar feeling: "*I avoid looking in the mirror because when I do so, I'm sad. It's not me anymore.*"

Discussion

Regarding the suffering of the women participating in the research, we can observe that the reports reveal a work overload and that they feel alone in taking responsibility for domestic work, which was socially learned as 'women's household chores'.

This notion of loneliness shown by women living with HIV is affirmed by Federici⁶⁽⁸⁰⁾ when he says that: "In the case of women, the attempt to educate men has always meant that our struggle was privatized and waged in the solitude of our room and our kitchen". Thus, the author draws attention to the concept of loneliness presented as this 'walking alone' in life as a woman. It is noteworthy that the 'HIV/AIDS Epidemiological Bulletin' published in 2018 shows that the psychosocial issues experienced by people with HIV are responsible for higher disease progression rates⁷. Therefore, if women with HIV are abandoned and feel alone (loneliness), as this paper suggests, we can conclude that this suffering from the psychosocial issues previously mentioned complicate the health status of these women vis-à-vis HIV.

In her gender studies, Federici⁶ points out that there is an automatic organization in the division of domestic work so that women are responsible for the tasks and that this culture affects all women without distinction. It is a social and cultural system that favors men, and domestic work must be naturalized and sexualized, becoming a woman's attribute in the name of 'relationships' and 'marriage' (even for those who are not married).

Given the above, it is noteworthy that the women participating in the research were not spared from this socially imposed place of service. We can observe that, for women living with HIV, these tasks become even more intense, reverberating in feelings of guilt and fear and of no longer serving the family, becoming more burdened with household chores than before diagnosis. As Ceccon and Meneghe⁸ point out, domestic work imposed

by the patriarchal structure is one more facet of the invisible violence that society imposes on these women living with HIV/AIDS since they are considered dirty people and, thus, excluded from spaces and social interaction.

Thus, the recurrent theme of loneliness in the participants' statements is not separated from the overload of domestic work since the very social, patriarchal, and masculinizing structure forges in women a way of perceiving their needs as 'whims'.

Therefore, we can affirm that women are not used to loving. Women don't learn to value their desires. Women have lived with the scarcity of love since their first appearances in the world, which means saying that the inner love proposed by hooks is not the lack of love from the other but how women, in general, learn through the (social and cultural) structure to despise and belittle their needs¹.

The dimension of loneliness for Federici⁶, recurrent in the statements of the women in the group, is a theme that health workers can take as an alert in their care practices since women's suffering in 'feeling alone' is just a visible part of an existence marked by silencing.

By mentioning silencing, we cannot merely point out that women have few opinions. It is not about this aspect. On the contrary, what is perceived in the macho culture is the mistaken understanding that women 'talk a lot' and 'complain too much'. Here is precisely what we want to point out: silencing does not imply not-speaking but sometimes talking too much without being heard, uttering opinions but not being considered, or fading and emptying; having desires and seeing their priorities postponed and sidelined before the needs of others. These and many other forms of silencing produce the effect of women's loneliness, which appears in all spaces and situations, often manifested in anxiety, depression, and sadness. In the case of women in the group with HIV, it was no different.

Given this, we understand that identifying potential psychosocial risks that affect the

health of women living with the stigma associated with HIV and the crossings imposed on these women by the macho and patriarchal structure are essential aspects of care. The results showed that loneliness could be characterized by someone's experience of feeling alone and evidenced by the deficiency or fragility of their affective networks, becoming a challenge for health professionals⁹.

In this context, we could observe these psychosocial risks from a closer perspective of these women's narratives during the therapeutic group. In the group, we noticed that the women needed to be strong to endure pain and suffering. Even in the face of the pain of an HIV diagnosis in which they would have to claim care (for themselves)¹⁰, or love themselves primarily, they experience abandonment and continue to meet the needs of others. In other words, these women feel guilty for not being able to do for others what they did before. Thus, they feel undervalued and continue to reaffirm their place of service, which was historically imposed on them, as mentioned earlier, to receive some care.

This study does not propose claiming the other's perspective of these women as if they were just abandoned. On the contrary, it points out that it is a social/cultural event. The scarcity of love is intrinsically linked to machismo's marks on women's bodies, which can affect the mental health of those living with HIV.

From the perspective of care, it appears that health workers do not understand love very well since the idea of 'love' has a relationship with care according to religious standards with a charitable vocation and generous care¹⁰ in the historical process of some professions, especially nursing. However, we should remember the academic effort to distance oneself from these notions of care as love and vocation, to conceive care from a perspective linked to the concepts of Social Determinants of Health (SDH) and sensitive care occurrences, no more from the Christian viewpoint¹¹. However, this love-care relationship is still obscure in health spaces.

Marinho points out that these cultural and social learning points are barriers created over a long time¹² and are the marks of the scarcity of love ethics affirmed by bell hooks observed in the participants' discourse. Therefore, this paper proposes the concept of love as different from charity, religious vocation, or even love as self-esteem, feeling, or emancipation. On the contrary, it presents it as a revolutionary ethics and an emancipating practice that results in self-confidence, self-respect, and self-esteem when effectively practiced and perceived.

hooks¹ says inner love can produce more affirmative existential forms, which emerge as affective ethics learned in the social field and can be exercised at any time and context by anyone, including women who experience diseases such as HIV¹³.

Therefore, cases and understanding that loving is a practice and that the social field interferes in human relationships, in the field of health, one shall understand that even the biological manifestations of HIV in women's lives also lack spaces for expressing their demands and appreciation of their feelings.

One of the feelings that often appears in a weaker tone in visits by health professionals and that, if valued, can qualify these women's mental health is the self-depreciation of their bodies. Discovering oneself with a disease like HIV can bring out all existential misery that is socially imposed, especially if it comes intertwined with other oppressions, such as racial and economic inequalities and sexual and age oppression¹⁴. The arrival of a tragic event, such as the diagnosis of a severe illness, sometimes makes these sick social processes within women much more apparent. Silvia Federici⁶⁽⁶⁰⁾ raises this issue of the dis-possession of women's bodies very clearly in her studies, as follows:

It depends on the appearance of one's own body whether one is going to get a good or bad job (within marriage or outside the home), whether one can gain some social power, some company to face the loneliness that awaits us in old age

- and, often, also in youth. We always fear that our bodies will turn against us because we can get fat, get wrinkles, age quickly, make people indifferent to us, lose our right to intimacy, or lose the chance to be touched or hugged.

The results showed that the participating women expressed disaggregation and disintegration of their bodies regarding their nature and that accumulating silencing practices emerged in the discourses within the group. This silencing could be heard by health workers in their offices only because of the illness, as a new suffering in the face of an HIV diagnosis.

However, when one understands how the concepts of inner love and loneliness apply to the suffering expressed by women living with HIV, one can observe that such silencing can be transformed into words, leaked affections, and instead of expressing suffering through interdisciplinary devices that enhance their existence as women in the world – including the various therapeutic groups (conversation circles, music therapies, reading groups, craft work groups, and dance groups) – and opening spaces for sensitive listening in individual sessions, letting the woman's subjectivity express itself and produce a perspective of herself.

Thus, the studies by Federici and hooks led health professionals to revisit the abyss that placed women vis-à-vis their bodies to compose care with them that includes a re-appropriation of themselves and a reconnection with their strengths¹. When care turns to women, and not the disease (stigmatized for anyone), we note some specific experiences precisely because they are women, which is why the authors of this paper tune their listening and analysis anchored in the concept of inner love in hooks and loneliness in Federici to think of more powerful ways of caring for women living with HIV, reflecting with them the social barriers that place them in disadvantaged places for the simple fact of being women. Yes, love heals!

Final considerations

This study observed the effects of machismo, sexism, and stigma associated with the suffering of women diagnosed with HIV. This suffering is expressed as affective and social helplessness women began to feel after being diagnosed with HIV, with significant economic and social consequences. The concept of loneliness collected and analyzed in this study as guilt and the feeling of ‘walking alone in life’ was striking in the results.

The study also revealed that women living with HIV express a feeling of impotence and dispossession of their bodies in the face of seropositivity. This lack of connection with their powers, the effects of structural machismo, domestic work overload, and the accumulated silencing practices weaken them and cause much suffering.

We should emphasize that the feminist studies presented here – Federici’s and hooks’ on loneliness and inner love, respectively – can be powerful tools to observe that suffering experienced by these women are aggravated precisely because they are added to the suffering of existing in the world as women.

Therefore, this study understands that identifying loneliness experienced by women living with HIV, the self-depreciation of their bodies, and the fear of seropositivity derive

from a cultural logic that oppresses women in any conditions of existence. The diagnosis is one of these conditions and not the only one.

Thus, the appropriation of inner love in hooks as affective ethics and a transforming practice can be used as a tool for health professionals to produce more sensitive care. Such a practice can place these women in more affirmative existential conditions. Therefore, there is urgency in constructing care strategies based on a logic of inner love for oneself. Love as an active exercise emerges as a strong possibility of revolutionary existence in the face of life’s adversities and gives way to reconnection of oneself as a woman, even living with HIV.

Collaborators

Paquiela EOA (0000-0002-0916-9203)*, Figueiredo EBL (0000-0002-5462-3268)*, and Muniz MPG (0000-0002-8615-7513)* equally contributed to the elaboration of the manuscript with the following steps: study design, data collection, data analysis and interpretation, discussion of results, writing or critical review of content, and review and final approval of the final version. Abrahão AL (0000-0002-0820-4329)* contributed to the review and final approval of the final version. ■

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