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ORIGINAL PAPER

An Initial Look into the Sexuality and Well-Being of Women Living with HIV: Making the Invisible Visible

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Abstract
This article focuses on the stories of women living with HIV concerning sexuality and well-being. Their stories counter the dominant perception of women's sexuality and challenge the social norms shaping their lives. Ten women between the ages of 28 and 55 were interviewed. At the interview time, five of the women were unemployed and one retired, four had a partner, and five had children. The semi-structured interviews were conducted following a face-to-face format in which the sex-affective area was explored, examining its relevance, the women's satisfaction, the difficulties they encountered, and the impact on their well-being. The results reflect the diversity of their experiences and the subordinate position they were in and their difficulties in meeting their sexual needs and achieving optimal levels of well-being. The data also reveals the status accorded to being a woman and being HIV-positive as factors affecting her sexual experience, as well as the difficulties she faced in obtaining satisfaction or care. Finally, this paper emphasizes the need to explore the obstacles in relation to living with HIV, including gender and sexuality, all of which must be taken into account in policy implementation and social policymaking.

Keywords Sexuality · Well-being · Experience · HIV · Women · Spain

Introduction

Sexuality is fundamental to the development of personal identity and establishing relationships with others. Bonding and contact are basic human needs. Satisfying affective or sexual needs is as essential as satisfying physiological needs, both of which are vital to survival and well-being [1, 2]. This construction is only possible in a social and cultural context where power structures and dynamics play an important role. Every individual may be in subordinate positions at certain times, but some power structures are more transcendent and more entrenched than others. Although distinguishable, gender and sexuality are closely linked and not only represent the classification of patterns, differential socialization, or the division of sexuality of labor, but they are also fundamentally power relations [3]. In

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this way, the sex-gender continuum and the sexuality dimension remain subject to strong social norms and pressures (based on biological differences), which regard citizens in unequal terms, causing the symbolic order to become subordinated [4]. However, most of the time, this subordination is not perceived as such by the dominated subjects. The forms of domination can also be quite subtle and sometimes even consented to and accepted by the dominated subjects as something inherent by nature, constituting a form of symbolic violence invisible to its victims and ultimately expressed via emotions [5]. Be that as it may, women occupy a subordinate position that is either subtle or explicit in social organization (women are considered for private domains and men for public ones, for example). Women's sexuality is likewise subordinate and invisible, and therefore, while this personal experience of life is always changing, it is only possible to understand it within the framework of intersubjective relationships that are permanently constructed and modified within a given social and cultural time-frame and context [6, 7].

On the other hand, since the introduction of combination antiretroviral therapy, in developed countries, HIV is increasingly perceived as a long-term illness and considered a disability, in which individuals experience complications of both the disease and its associated treatments [8]. These challenges can be understood as one component of a more extensive set of limitations at the individual or societal level, encompassing 'impairments, activity limitations and participation restrictions' (p. 10) that span physical, individual, and societal perspectives [9] and are necessary for a comprehensive evaluation of the experience of living with HIV and for improving associated care, treatment and support. Given the above, receiving an HIV diagnosis represents a vitally challenging and complex situation, not only because of the medical implications but also because of the interpersonal and social implications associated with it, which can lead to traumatic experiences with profound consequences in the intimate and sexual spheres [10, 11]. Studies on the social implications of HIV throughout the history of the disease have focused primarily on the individual and, in particular, on the coping mechanisms and stigma associated with living with HIV [12]. Meanwhile, an emerging and growing sector is dedicated to exploring everyday life and the multiple identities that interact in complex ways, incorporating new elements of analysis such as gender or sexuality, among others. This analysis of everyday experiences is a focus of growing interest for the scientific and professional community [13, 14].

According to global data, around fifty percent of people with HIV are women [15]. Furthermore, the nature of HIV, regarded as synonymous with the illness and strongly linked to sexuality, makes it highly stigmatized [16]. Although social discourse has changed over the years, the dominant narrative regarding risks and social pollution have favored a cultural context based on fear [17], thereby placing all responsibility on the individual.

Concentrating on protection has tended to obscure the positive view of sexuality from a sexual needs and rights perspective, which, at the same time, has also identified women as being in permanent need of protection, rather than pleasure-seeking [18].

While gender is a relatively historical and social construction made up of meanings and symbolization of the anatomical differences between men and women, it includes social assignments, "forms of being" which are unique to each, effectively denying heterogeneity and uniqueness, with the former being given a social advantage over the latter [19]. Gender constructions impose conditions of social vulnerability and possibilities and limits on daily life [20, 21]. Research on women's sexuality has focused primarily on specific behaviors or physiological changes, with subjective experience related to sexuality and sexual life relegated to the background [22].

These conditions apply to sexuality and to HIV, both of which inhabit the body. A dominant and somewhat authoritarian discourse allows us to talk about sexuality and

HIV related to the body from a medical perspective [23]. We therefore talk about disease prevention and sexual health (of others, not of those living with the virus), as opposed to sexuality. As a result, the tension between pleasure and danger surfaces in discussions of sexuality. For women, the discourse on pleasure is delegitimized, associating risks with inappropriate and undesirable behavior.

Those who experience pleasure disallow sexuality and censure bodily desires; these women are exposed to life on the margins stemming from fear, violence, and guilt. The sex-gender structure in which women's subjectivity has been constructed [25], with the understanding that body, pleasure, and desire are beyond their control but instead under male domination, imposes severe limitations on their capacity for autonomous action and care, especially within the realm of sexuality and intimate relationships [26].

Sexuality confronts the female body as the erotic objective of a dominant model. For many women, the diagnosis transforms their sexuality and body into something that must be censored. An undesirable image of themselves makes it very difficult to adequately meet their sexual needs and to take care of themselves to the point of being satisfied [27]. Sexual satisfaction, that is, the perception of well-being experienced concerning sexual and erotic life, is a central component in resolving women's sexual needs that have remained largely unexplored [22]. The erotic experience also constitutes an affective experience. Such individual values (e.g., sexual positive or negative beliefs), together with relational values, are the most powerful influences on sexual satisfaction [28].

Bearing all this in mind, we must recognize, firstly, that being a woman and living with HIV conditions one' s experience in the intimate and sexual sphere; and secondly, that personal experience and the way it affects one' s well-being is unique to each individual, with age and many other aspects playing an important role [29].

Despite interest in the sexuality of women living with HIV, few studies have explored the experience of women living with HIV from their perspective [30, 31]. This allows us to appreciate the complex relationships that exist among the various elements and how they influence, in this case, women's ability to satisfy their sexual needs and ensure their well-being.

Our Research

In this research, through the women participants' stories, we have gained access to their sexual experiences, intimate relationships, and well-being, which have been affected by multiple elements, including the fact that they are women and the role that HIV plays in their lives. Through their stories, we seek to understand how they have addressed their sex-affective needs and the difficulties and support they have encountered in this area related to their well-being. Through these interviews and the stories shared, these women have provided us with insight into who they are and what has influenced them [32, 33]. This has made it possible for us to explore the complex interconnections of life and, at the same time, has allowed the women to reflect and articulate in their own words what they deem to be important.

Considering all of the above, the question arises: what difficulties do women living with HIV face in fulfilling their sexual and romantic intimacy needs? What support do they receive in doing so? How does it impact their overall well-being? The results section below will address these questions in the context of four analysis categories: (1) the role of sexuality; (2) sexuality as a woman living with HIV; (3) sexual satisfaction among women living with HIV; and (4) care and self-care in the context of sexual intimacy. The

HIV-positive women interviewed for this study identified varying difficulties, supports, and impacts concerning each of the aforementioned categories of analysis.

Methodology

Design

A qualitative research approach was adopted to explore the above questions and gather and understand the experiences of women living with HIV. This work is part of a more extensive study in which the main goal is to understand the significance of different aspects involved in the lives of women living with HIV [34]. In this regard, the study seeks to understand the web of intersubjective relations while specifying the meanings that sustain identity processes and reflect lived reality and context in a very authentic way [35, 36].

Participants

Ten women living with HIV participated in this study. In addition to being women who live with HIV, the inclusion criteria included being over 18 years old and having some contact with a local non-profit entity that works with sexuality, sexual health, and HIV prevention and intervention. The sampling was intentional. Of the 28 women initially contacted, 18 refused to participate, citing, in some cases, fear of visibility.

Once the above conditions were met, the group of participating women proved to be heterogeneous, having vastly different lifestyles. More specifically, the participating women were between 28 and 55 years of age; four had partners and five had children at the time of the interview; eight were cohabiting, some with their partners, others with family, others with friends and one in a foster home. Although they had all been residents of the same community for many years, their backgrounds were quite diverse. Lastly, five of them were unemployed and one was retired.

Procedure

A local entity contacted us to collaborate with them on finding ways to reflect on the reality of women living with HIV, as evidenced by their professional experiences. Together, we developed a project that would examine multiple contexts of women's lives to comprehend their life experiences and foster their well-being. The participants were recruited from various cities and towns in a Spanish autonomous community by the professionals of the local entity, who then contacted the women by telephone or personally during any of the entity's activities.

Through semi-structured interviews, we explored different aspects of the participants' profiles based on various issues, including social, partner and sexual relationships, citizenship, self and others care, and future projects. As has already been noted, this work focuses on analyzing participants' experiences and feelings associated with sexuality and how such experiences and feelings condition or otherwise affect their well-being. All interviews lasted approximately 90 min and were conducted in a private room provided by the local entity. The information was recorded via audio to pay full attention, with notes taken as necessary both during and immediately after the interview. Subsequently, the interviews

were transcribed for further analysis. Once transcribed, they were made available to participants, although none of them made any changes.

The entire research process was carried out in compliance with ethical safeguards for the participants. A complete outline of the objectives of the work was developed in conjunction with the local entity, as well as the various stages, the topics around which the interviews would revolve, etc. Information regarding the objectives was shared with the participants, informed consent was obtained for participation, and authorization to record the interviews, confidentiality was ensured. It was communicated that the decision had been taken to publish data using fictitious names. The right to withdraw from the study at any time or to refuse to answer any questions without justification was also affirmed. Access to the transcribed interviews was granted if any participants wished to make any changes or eliminate any of the items. Interview data were analyzed using an inductive thematic analysis approach [37], in which similarities and differences of experience were systematically identified and grouped into relevant analytical themes. In the following sections, the data discussion is structured around two main issues: participants' experiences of sexuality and how these experiences pertain to their well-being.

Data Analysis

Data processing and analysis were carried out using a thematic coding process. Categories of interest were developed, and the two authors of this paper coded the transcripts of the interviews in which the relationships between the different categories were further investigated using an inductive thematic analysis approach, identifying similarities and differences in the stories for the thematic organization [37]. This was done separately at first, then jointly, and finally using consensus coding among researchers to analyze all the interviews [38]. The data were then presented along two main lines, the participants' perception of sexuality with respect to their well-being and how this perception is affected, among many other issues, by being a woman and being HIV-positive.

Results

Following this paper's purpose, two key issues are addressed about the experiences of women living with HIV: affective-sexual needs and well-being. The data analysis in this work shows that the sexual experience and the resolution of sexual needs are strongly conditioned by the virus and the woman's condition, affecting her life course and well-being in numerous and varied ways. Below are several difficulties, supporting aspects, and well-being implications under each heading.

The Role of Sexuality: Meaning, Invisibility, Social Norms and Changes Throughout Life

As a central aspect of human experience, sexuality alludes to human beings' sex-affective experience and intimacy and pleasure with oneself and others. This global vision is also rather specific to women, in that they value sexual experience as a set of intertwined elements that promote well-being::

- Q.: What role does sexual intercourse play in a couple's life?

- A.: Well, passion, at the beginning […] but as the years go by, libido decreases and it remains, it is still important, because it is important from time to time, don't you think? It doesn't have to… I mean, there are many kinds of sex, and often with a little petting you are happy as a clam, right? But, I mean, I don't think it's the most important thing for a couple, because lots of times having someone's company matters more than the sex (Participant 4, 55 years old, in a romantic relationship).

As one woman previously stated, a woman does not own her pleasure, and HIV constitutes a threat to her own body and the bodies of others, therefore converting her body into an ambivalent element of pleasure and pain, defined by repression. One of the women interviewed explains this:

- Q.: And what role does sexual intercourse play for you in…?
- A.: Right now, I don't need it for anything, and I don't even think about it.
- Q.: Are you satisfied?
- A.: No, I'm neither satisfied nor dissatisfied; I don't think about it; I don't need it. It's not an essential thing in my life right now, it isn't anything at all. In fact, it hasn't even crossed my mind (Participant 6, no age, in a romantic relationship).

At times, sexuality does not appear as an explicitly denied dimension, placing sexual relations in a context of freedom and decision making, but rather one that is linked to whether or not one is in a relationship. In recent years, however, sexuality is no longer regarded as a prohibited aspect for women. As one of the participants puts it:

- Q.: How important is sexual intercourse to you?
- A.: Sexual intercourse, I don't know, sex is very important, but if you don't have taboos, there's no priority to this or that.
- Q.: In other words, it is important to you.
- A.: I believe that for a couple, sexual intercourse is important. (Participant 6, no age, in a romantic relationship).

The previous paragraph reflects the union between sexual relationships and partner relationships. Numerous works have delved into how sexuality, which has been influenced since childhood by the dominant masculine system, limits women's experience, and neither positive sexual beliefs, nor desire nor, of course, sexual practices are permitted if it does not fall within the framework of a stable, definitive and regulated adult relationship.

However, we also find women who portray sexuality as of great importance, but at the same time experienced in an unmistakably unique way, and in which it is essential to accept vital changes. A person's need for interaction, intimacy, contact, pleasure, and affection never ends, albeit the way it is expressed can vary, as expressed by one of the women interviewed:

> It is important, for both of us, the thing is, I mean, because of our age and where we are at in life, since we already have our issues, which we continue to struggle with, because even though we want to remain active, we don't want to become apathetic, because come on, I know that in theory, even though your body often wants to pull you in another direction, when you're in menopause, as I am already, does not mean the end of sexuality, in fact, it's when a woman can truly enjoy her sexuality, because the whole question of motherhood is over, for example, that's been taken away, and

your body keeps going, and I, I can attest to this, I have insisted that it has to keep going." (Participant 4, 55 years old, in a romantic relationship).

Sexuality as a Woman Living with HIV: the Body as an Object, Violence, Disclosure, Vulnerability, and Submission to Care

Sexual experience changes the moment the diagnosis is received. Sexuality, in one respect, can be a means of control within intimate relationships. At the same time, HIV may be seen as an intolerable aspect of a body that is erotically desirable, most notably in women. This may be seen in the following story:

> Then my daughter's father came down to see her, and they (the doctors) told him, thinking that I had already told him, and well, it was horrible, it was horrible, that is, [from] that moment on he didn't touch me, I thought about pulling myself away, I, well, I don't know, he called me everything, he said everything, it was really bad (Participant 4, 55 years old, in a romantic relationship).
> Another woman explained her experience as:
> A trauma, a total trauma [...] I've never had a viral load, so thanks to that I haven't been able to pass it on to anyone, but I don't care because when you know you have it (HIV), it's a trauma, or I mean, it's not... When my daughter's father found out, the first thing he did was to cut off sexual relations with me. So for me, that was, as you can imagine, a trauma. So when you have your partner whom you're going to have a child with cut off sex, well... (Participant 2, 34, no partner).

In this regard, the affective implications that this type of situation has on people are often far-reaching, and the damage, related to self-contempt, long-lasting. This damage arises from the stigma of the aforementioned deep-rooted social construction, which affects how people address their sexual needs and the lack of understanding by those who are significant to the HIV infected person, especially in those vital moments of change and vulnerability.

This situation of perceived vulnerability and risk is validated in different situations in which disclosure may not only lead to rejection and abandonment but may also be used in multiple coercions, including sexual coercion, as expressed by one of the women:

- Q.: And did you tell anyone in your family?
- A.: I didn't get around to mentioning it […] I only told a friend of the family, who then ended up wanting to go too far with me. (Participant 8, 36 years old, in a romantic relationship).

Nonetheless, the social construction of gender is a central element in the analysis of the experience of women living with HIV. On the one hand, the conception of the feminine gender as bearers of affection and less capacity to make decisions makes them passive subjects, destined to the dominant ones' complacency. On the other hand, living with HIV forces them to abandon their desires regularly. Explicitly, some of the women interviewed have stated that the very fact of being a woman conditions the experience of sexuality, in particular, life with HIV:

> It was many years ago that, with age, I wanted us to go on vacation, and I didn't want it to get to the point of: "put it on, put it on," "I don't want to," you know? Because it's a punishment... not so much for the man, but for the woman when your partner

doesn't want to wear it, she doesn't want him to wear it, she's forcing him to... Well, one of two: either you run out, or you have to confess, and I didn't want to have to say anything. But I got up the courage and told him. (Participant 2, 34 years old, without a partner)

The patriarchal discourse and stigmatization of HIV are strongly internalized, sometimes converting women into oppressed subjects and oppressors of their person, denying themselves the possibility of rekindling an interest in intimacy, as evidenced in the following passage:

- A.: No, because, of course, with what I have [referring to HIV], no, I mean, I take it for granted, I don't imagine anyone capable of saying anything. So when he told me, I thought, "You must be drunk or something," because if he's calm, if he really thinks about it, he probably wouldn't say that. But him being calm, there was nothing (between us), so I told myself, "It can't be," and I almost didn't believe it. (Participant 3, 43 years old, without a partner).

However, we also found other situations in which the diagnosis was not linked to a history of abandonment by an intimate partner, as one of the participants pointed out:

- Q.: Now, X, does your partner know your situation? Does he know that you have HIV?
- A.: Yes.
- Q.: How does he deal with the issue?
- A.: No, well, because he also happens to be HIV-positive and so forth, but well, we did a good job of addressing it from the beginning, because neither of us had it initially, and we acquired it at the same time, and well, I told him, I said, "have you had these tests done?", "yes," "have they given you the results?", "no," " they told me, they want to do them again." And when he was given the results, it was the same, wasn't it? "And now what do we do," "how do we proceed? well, kid, we take our medicine and go on living," and we haven't really had any problems at all. (Participant 9, 52 years old, in a romantic relationship).

However, this does not detract from the fact that both members of the couple are living with HIV and became aware of it simultaneously, which may mediate this particular situation. Consistent with this, and taking into account that in this case, the relationship had already been established, many people living with HIV prefer to have partners who also have the HIV due to the belief that the shared nature of the situation will make it easier. This was expressed by one of the women:

- A.: Well, I've had partners who were positive too, there was no problem there, but…
- Q.: And why do you say there's no problem?
- A.: Being positive…
- Q.: Both of you.
- A.: Well, you don't need to explain anything. I mean, yeah, if you decide to take care of yourself but, ok, you still use a condom, but it's not the same, it's not this scary thing anymore because that goes away with the other person, when they know, of course. Ok, what do I know, even if you know that maybe they have it (HIV) and you don't use a condom, but at least you don't have this uncontrollable fear in your head, fuck. (Participant 2, 34 years old, without a partner).

Sexual Satisfaction Among Women Living with HIV: Sex-Gender System, Guilt and Fear, and Intimacy

As a consequence of the new discourses in which sexuality is accepted as an essential component in people's love lives, it seems that a more positive sexual vision has spread and that sexual double-standards have been censored. However, this has not been fully established, not for everyone, and normative beliefs associated with men and women persist, as evidenced by one participant:

- Q.: Do you consider yourself to be sexually satisfied?
- A.: Yes, well, lately, he's been feeling a little tired, and I say to him, "they say it's the women who have headaches," "well, it doesn't bother me," and well, lately I've kind of been on a diet but whatever, there are toys, and that takes care of it. (Participant 4, 55 years old, in a romantic relationship).

In addition, the predominant position blames those living with HIV for the virus, establishing a cause-effect relationship between a given practice and a given consequence. Having satisfactory sexual relations while under constant pressure in every intimate situation can be extremely difficult. One of the women describes it as such:

> I'm good, but even so, there are times when you say shit, if this happens or I can't enjoy that anymore because I have this... Then... [...] It has changed the way I think, I've become more cautious about everything, you know? I'm afraid of what I might do in terms of having fun, to the point in which I've set limits to my own enjoyment. (Participant 7, 28 years old, in a romantic relationship).

Another woman expressed how she avoids some practices of sexual pleasure due to HIV-related scares:

> But I, he goes down on me (referring to the practice of cunnilingus), and what do I say? No, no, not today. Tomorrow I say: no, not today. So I have to say, hey, this way, over here, over there, but I have to say that I'm HIV positive." (Participant 1, 48 years old, without a partner).

At times, sexual activities are curtailed due to the fear that someone else may become infected, even in non-risk or protected situations. Finally, sexual satisfaction is linked with affection, regardless of whether or not sexual relations occur outside the intimate relationship, as can be seen in the following fragment.

- Q.: In those situations when you were not in a relationship, have you felt sexually satisfied?
- A.: No. No, because no. Because for example, you go, you sleep with someone, yeah, you have your one-night-stand, but it's not the same, you say well, you got there, I've taken care of it, and that's that, but it's not.
- Q.: What do you lack in that…?
- A.: Well, that's it, finding someone. I'm just very much the kind of person who likes to be in a relationship." (Participant 1, 48 years old, without a partner).

Care and Self-Care in the Context of Sexual Intimacy: Stigma, Guilt, Lack of Resources and Sexual Male Attitudes Domination View

The fears and the stigma attached to having the virus perpetuate the idea that you will permanently need to take extra precautions, especially in sexual relations, always having to think about the other person, and much less about yourself, as can be seen below:

> Well, because he doesn't have it... I mean, even if I know I can't give it to him, or so the doctors say, it doesn't matter; it's scary. There is always this fear of the slightest possibility of; I don't know, the idea of it is horrible, horrible because the heat of the moment is combined with fear. And on top of that, you are also human and... it's just horrible, you know, but... (Participant 2, 34 years old, without a partner).

This, at the same time, coexists with the need to relieve oneself of guilt, as seen in the following paragraph:

> Well, if he has the virus, he has it... if you have it, then go and get tested, cut the bullshit, stop insisting, I've got enough problems of my own, go and get tested; if you don't get tested, that's your problem. It's really complicated". (Participant 2, 34 years old, without a partner).

In connection with the above, it seems reasonable to reflect on the individual and collective duties and rights.

Finally, the limitations that women sometimes encounter in the provision of care and self-care are also visible, including a lack of personal and interpersonal resources to deal with the consequences of the virus in the context of intimacy, as one of the women states:

- Q.: And to what extent do you think, X, that your life has changed since becoming aware that you have HIV?
- A.: Since my husband wasn't able to use a condom, I often told him that I had a stomachache, a headache, my period, when I had it, and that I was using tampons because even though I didn't have it, I wore tampons. I said, "I can't, I'm on my period and stuff, and I don't like that it's unhygienic. And of course, I avoided it many times until he realized it and said, "X, you don't have your period, because although I am a man, I know how periods work, and of course, you don't have your period, right now." I asked, "How do you know?", he said, "Oh, it's my thing, I'm investigating you. And of course, until I sat down with him and told him since he couldn't use condoms, I was afraid he might get infected, and I had enough of my own stuff to deal with without adding that on top of it. (Participant 8, 36 years old, in a romantic relationship).

In addition, the previous fragment highlights how the phallocentric vision (yet another example of the symbolic domination of the masculine over the feminine) focuses pleasure exclusively on coital relations and assigns a well-defined and dichotomous role with regard to heterosexual relations, with the masculine playing an active role and the feminine a passive one.

Without a doubt, sexuality takes on different meanings and characteristics for each woman living with HIV; however, these values have developed throughout her life and are linked to the social construction of sexuality and all the elements that permeate sexual experience, such as being a woman living with HIV, which cannot be ignored when exploring this dimension and the possibilities of working in this field.

Discussion and Conclusions

Sexuality is a core aspect of well-being, an inevitable component of being human, strongly conditioned by social norms that make it a particularly complex realm with its internal dynamics, which is ever-present and essential to oneself well-being [2].

This article drew on interviews with women living with HIV to highlight the participants' experiences of sexuality and how these experiences pertain to their well-being. Despite the diversity of sexuality and well-being experiences, some commonalities are reflected in the following selected themes. Specifically, many women reported that difficulties, supports, and effects on their well-being relating to their sexual and romantic intimacy needs arise from: (1) the frequent invisibility and/or denial of sexuality in various guises and, particularly, of pleasure, or the link between pleasure and affectivity [17], (2) the transformation of sexuality from the moment one knows they are living with HIV [11], (3) the relationship between sexual experience and care for oneself and others [39], and (4) the implications on sexual satisfaction and well-being [18].

In terms of the invisibility and/or denial of sexuality, our results showed that beyond the utopian ideal of construing sexuality as free from oppressive constraints, the experience of sexuality among women living with HIV is fraught with the tension derived from an essentialist education. This education depicts these women's sexuality, framed in socio-cultural normality [40], in which they are not masters of their pleasure [27], incorporating a deep sense of repression throughout their lives [41] and in many cases remaining denied and invisible. According to this, non-coital practices as forms of intimate relationships, for example, are also invisible and undermine women's autonomy as subordinate to coital practices and male decision-making [42].

Moreover, these women's sexual experience changes the moment they become aware that they are living with HIV, taking into account that sexuality is used to control intimate relationships and that the presence of HIV becomes a threat to their own and others' bodies, resulting in her becoming undesirable [27]. At the same time, there are also notions that a diagnosis is a form of punishment for past sexual practices, which generates discomfort, guilt and fear, facilitating the avoidance of sexual relations [43]. At other times, the women try to establish relationships with other people who are HIV-positive. In this regard, some studies indicate that many people living with HIV prefer to have partners who also carry the HIV, due to the belief that the shared nature of the situation will make it easier [44].

Conversely, their sexual experience is modulated by care for themselves and others, in which guilt and fear arise, in which there is a constant fear of transmitting the virus to the other person, in line with previous studies [45]. Moreover, as women are the subordinate social category, they are seen as instruments designed to serve male pleasure from the point of view of heterosexual relations [27]. The weight of these aspects is that they transcend the intimate relationship, the time shared, the commitment, the respect, and the human being's value, extending as far as violent situations [46]. On the other hand, however, ethics must be taken into account at the decision-making level (e.g., ensuring proper condom use), which could constitute a key element in promoting well-being and sexuality, with the understanding that ethical behavior in relation to oneself and others is desired [47].

Finally, and hardly surprisingly, all of these aspects have implications for sexual satisfaction and well-being. Recognizing that sexuality is intrinsic to human beings and

that sexual satisfaction is an essential element of one's well-being [18], HIV and the stigma associated with it have a substantial impact on well-being [34].

Those aspects most closely associated with sexual satisfaction and well-being in women are feelings of intimacy, trust, and concern about the other person [48, 49]. Indeed, some studies conducted with pre-pubescent boys and girls indicate that young women say they feel guiltier about having fantasies and desires than men do [50]. Data such as these would help to explain the repressive context that conditions sexuality as something that is only conceived in the context of a couple [43].

As other studies have found, satisfying sexual life is an essential component of health and well-being. For that reason, the high rates of sexual inactivity observed among women living with HIV, coupled with their experiences of HIV-related stigma and their generalized sexual dissatisfaction, underscores the need to revisit the narrative about sexual activity among women living with HIV [51].

In short, this work is innovative because, despite extensive research in the field of infection regarding its consequences for women, sexuality, the central theme of this work, has not been explored to the same extent and has been relegated to the background. Like other previous studies (both quantitative and qualitative), this study highlights some of the difficulties faced by women living with HIV in addressing their sexual needs, including how their well-being is affected. Examples of such effects on well-being include the significant life changes experienced after diagnosis, the challenges of living with HIV, the perceived obligation to disclose HIV status to sexual partners as a barrier to establishing long-term romantic relationships, and the experience of sexual dissatisfaction [51, 52]. However, these effects are examined here in the context of how gender and contagion, with respect to lack of legitimacy and agency, affect the resolution of sexual intimacy needs [27, 29, 52]. Besides, our results provide a better understanding of difficulties (showed as more frequent than support aspects), support, and implications for the well-being of women living with HIV regarding different sexuality topics. This work was possible because it focused on delving deeper into the issue of sexuality through private and credible interviews conducted according to ethical standards. Despite some similarities to the findings of previous studies [10], this study adds a global perspective of the subjective experience of sexuality. It includes several elements that have not been explored as a whole until now (e.g., the role of sexuality, sexual satisfaction, stigma, self-care, well-being). As a result, some light has been shed on the implementation of professional, social, and academic initiatives that improve these women's personal and social well-being and the greater social context.

Limitations of the Study and Future Lines of Research

Although this work evidences interesting contributions toward understanding the reality of women living with HIV, it is not without limitations. In this sense, we are aware that, despite the sample's heterogeneity, all women had some type of contact with the local entity dedicated to work on sexuality. This indicates that we have accessed women who, in some way, have shared their circumstances and needs with a support entity, but not those who are in a situation of perhaps greater isolation. Notwithstanding, the condition of the women in relation to visibility and isolation was also quite heterogeneous.

Moreover, other aspects that could have contributed to subsequent analysis, including origin, socio-economic status, desire orientation, etc., which could be of particular interest in future studies, were not explicitly anticipated in this study's design. Accordingly, it is crucial that the results not be taken to consider women living with HIV as a homogeneous

group, as yet another (subordinate) normative identity. A clear attempt has been made to emphasize the heterogeneity and uniqueness of experiences. However, the persistent problems in the sexuality of women living with HIV have a bearing on the seriousness they address. Besides, the sample's representativeness was not guaranteed due to the lack of data on population size. However, the sample was intentional, and the study was developed following a qualitative methodology. With this in mind, these data are not generalizable. However, these data provide insight into the experience of women with HIV in terms of sexuality. Given the qualitative nature of the study (with semi-structured interviews), it is not fully replicable. However, it might be a useful guide for exploring specific aspects of sexuality in future research, both qualitative and quantitative. The main components of this research (e.g., the role of sexuality, sexual satisfaction, stigma, self-care, and others care) could be explored further through additional qualitative studies among other women living with HIV in order to broaden the analysis of these elements. These components could be explored too not in women, but in men and other gender identities. Alternatively, future qualitative studies could go deeper into one or more sub-topics studied here, such as self-care, discrimination situations, etc. However, quantitative studies could also be designed to explore the associations between these subtopics or assess which of these aspects of sexuality are most relevant to these women's well-being.

Practical Implications

The results of this work have some implications for different areas. On the one hand, the results encourage professionals to become aware of specific aspects related to the difficulties in satisfying sexual needs and its implications on well-being, and the role that gender plays in this process. Furthermore, our study can help academics, policymakers, and organizational leaders think differently and critically analyze emerging and interconnected challenges regarding gender, HIV infection, and sexuality.

Additionally, there is a need to promote more resources and programs that address sexuality-related work in various interrelated social, educational, and health sectors so that the possibilities for addressing and improving well-being can be expanded. Their absence is further evidence of the fact that they are of marginal importance.

In particular, the possibility of approaching the intimate and sexual sphere from an erotic perspective, in which the body is understood as a pleasant habitat and sexuality as a need and a right, rather than a privilege, must be promoted.

Furthermore, working on reducing the internalized stigma that immobilizes women and deprives them of their own personal and interpersonal resources to cope with many of the situations they face while simultaneously promoting responsibility for self-care could be extremely worthwhile.

The work of zero tolerance towards violence also needs to be developed further through socio community proposals, procedures, and protocols that effectively guarantee solutions to the needs, including these women's sexual needs. The integration of the information provided by the women themselves towards the training of professionals working in the areas of sexuality, HIV, and women, among others, is essential to ensuring that the information is incorporated, and hence is able to broaden thoughts and actions in this field. Finally, these findings could help professionals reach out to others with experiences or situations of disability that have not been revealed, allowing them to identify potential risk situations and address workers' sexual needs, stigma, and related feelings. Possible interventions to improve sexual satisfaction and well-being among women living with HIV could explore:

the effects of invisibility and/or the infection denial in intimate relationships; the impact of the onset of the HIV diagnosis on sexuality and general well-being; or how to promote self-care and others-care (with treatment adherence, barrier methods in sexual contacts, etc.).

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Code Availability The coding process could be consulted via email to the authors.

Declarations

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval/Research Involving Human Participants and/or Animals This study was carried out with the participation of individuals who voluntarily accepted to participate, and all procedures carried out in this study were in accordance with the ethical standards of the Ethics Committee of the University of Cantabria and the Declaration of Helsinki of 1964.

Informed Consent All participants voluntarily signed an informed consent form.

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References

1. Deci, E.L., Ryan, R.M.: Intrinsic motivation and self-determination in human behaviour. Plenum, New York (1985)
2. López, F.: Necesidades en la infancia y en la adolescencia: Respuesta familiar, escolar y social. Pirámide, Madrid (2008)
3. Herrera, C., Campero, L.: The vulnerability and invisibility of women facing HIV/AIDS: constant and changing issues. Salud pública de Mexico **44**(6), 554–564 (2002)
4. Fernández-Rouco, N., Carcedo, R.J., Yeadon-Lee, T.: Transgender identities, pressures, and social policy: a study carried out in Spain. J. Homosex. (2018). https://doi.org/10.1080/00918369.2018.1550330
5. Bourdieu, P.L.: Dominación masculina. Anagrama, Barcelona (2000)
6. Calogero, R.M., Siegel, J.A.: Widening Understandings of Women's Sexual Desire: A Social-Ecological Lens. Arch. Sex. Behav. **48**(6), 1693–1698 (2019)
7. Grimberg, M.: Género y vih/sida: un análisis de los diferenciales de género en la experiencia de vivir con vih. Cuadernos médico sociales **68**, 41–54 (2000)
8. Rusch, M., Nixon, S., Schilder, A., Braitstein, P., Chan, K., Hogg, R.S.: Impairments, activity limitations and participation restrictions: prevalence and associations among persons living with HIV/AIDS in British Columbia. Health Qual Life Outcomes **2**, 46 (2004). https://doi.org/10.1186/1477-7525-2-46
9. World Health Organization: International classification of impairments, disabilities and handicaps (ICIDH). The World Health Organization, Geneva (1980)
10. Carter, A., Greene, S., Money, D., Sanchez, M., Webster, K., Nicholson, V., Pick, N.: The problematization of sexuality among women living with HIV and a new feminist approach for understanding and enhancing women's sexual lives. Sex Roles **77**(11–12), 779–800 (2017)
11. Ho, S.S., Holloway, A.: The impact of HIV-related stigma on the lives of HIV-positive women: an integrated literature review. J. Clin. Nurs. **25**(1–2), 8–19 (2016)
12. Dale, S., Cohen, M., Weber, K., Cruise, R., Kelso, G., Brody, L.: Abuse and resilience in relation to HAART medication adherence and HIV viral load among women with HIV in the United States. AIDS Patient Care STDS **28**(3), 136–143 (2014)

13. Cusick, L., Rhodes, T.: The process of disclosing positive HIV status: findings from qualitative research. Cult. Health Sex. **1**(1), 3–18 (1999)
14. Grimberg, M.: Narrativas del cuerpo. Experiencia cotidiana y género en personas que viven con VIH. Cuadernos de antropología social **17**, 79–99 (2003)
15. Bolaños Gutiérrez, M.R.: Atención a mujeres con VIH/sida. Revista Cubana de Medicina General Integral **36**(1), e1073 (2020)
16. Lawless, S., Kippax, S., Crawford, J.: Dirty, diseased and undeserving: the positioning of HIV positive women. Soc. Sci. Med. **43**, 1371–1377 (1996)
17. Parker, R., Aggleton, P.: HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Soc. Sci. Med. **57**(1), 13–24 (2003)
18. Szasz, I., Salas, G.: Sexualidad, derechos humanos y ciudadanía. Diálogos sobre un proyecto en construcción. El Colegio de México A.C, México (2008)
19. Stryker, S.: Transgender history, homonormativity, and disciplinarity. Radic. Hist. Rev. **100**, 145–157 (2008)
20. Brody, L.R.: Gender, emotion, and the family. Harvard University Press, Cambridge (1999)
21. Fetterolf, J.C., Sanchez, D.T.: The costs and benefits of perceived sexual agency for men and women. Arch. Sex. Behav. **44**(4), 961–970 (2015)
22. Bridges, S.K., Lease, S.H., Ellison, C.R.: Predicting sexual satisfaction in women: Implications for counselor education and training. J. Couns. Dev. **82**(2), 158–166 (2004)
23. Le Breton, D.: La sociología del cuerpo. Editorial Nueva Visión, Buenos Aires (2002)
24. Clavreul, J.: El orden medico. Argot, Barcelona (1983)
25. Rubin, G.: El tráfico de mujeres: notas sobre la "economía política" del sexo. In: Lamas, M. (ed.) El Género: La construcción cultural de la diferencia del sexo, pp. 35–96. Porrúa/PUEG, México (1996)
26. Herrera, C., Campero, L., Caballero, M., Kendall, T., Quiroz, A.E.: Cuerpo y sexualidad en la experiencia de hombres y mujeres con VIH: una exploración de diferencias y coincidencias de género en México. Estudios Sociológicos **27**(79), 147–170 (2009)
27. Grimberg, M.: Sexualidad, experiencias corporales y género: un estudio etnográfico entre personas viviendo con VIH en el Área Metropolitana de Buenos Aires, Argentina. Cad. Saude Publica **25**, 133–141 (2009)
28. Ortiz, M., Gómez, J., Apodaca, P.: Apego y satisfacción afectivo-sexual en la pareja. Psicothema **14**(2), 469–475 (2002)
29. Squire, C.: Neighbors who might become friends: Selves, genres, and citizenship in narratives of HIV. Sociol. Q. **40**(1), 109–137 (1999)
30. Anguiano, V.F.: Otro VIH/SIDA: relatos de la vida en la era del tratamiento antiretroviral. Tesis Doctoral. Universidad Iberoamericana, México (2018)
31. Carrasco, P., Gutiérrez, A.A., Loayza-Godoy, C., Ferrer-Lagunas, L., Trujillo-Guarda, C., Fernández-Sarmiento, A.: Pérez-Cortés CPC: Cómo entender la experiencia de personas que viven con VIH: implicaciones para la clínica y la investigación. Aquichan **13**(3), 387–395 (2013)
32. Crossley, M.L.: Narrative psychology, trauma and the study of self/identity. Theory Psychol. **10**(4), 527–546 (2000)
33. Sarbin, T.R.: Narrative Psychology: The Storied Nature of Human Conduct. Praeger, NewYork (1986)
34. Haya, I., Fernández-Rouco, N.: I do not see myself as part of anything: learning from the subjective narrative of women living With HIV in Spain—clues to rethinking social work intervention. Br. J. Soc. Work (2019). https://doi.org/10.1093/bjsw/bcz054
35. Banister, P., Burman, E., Parker, I., Taylor, M., Tindall, C.: Qualitative methods in psychology. A research guide. Open University Press, Philadelphia (1994)
36. Taylor, S., Bogdan, R.: Introducción a los métodos cualitativos de investigación. Paidós, Barcelona (1996)
37. Braun, V., Clarke, V.: Using thematic analysis in psychology. Qual. Res. Psychol. **3**, 77–101 (2006)
38. Ahrens, T., Chapman, C.S.: Doing qualitative field research in management accounting: Positioning data to contribute to theory. Acc. Organ. Soc. **31**(8), 819–841 (2006)
39. López, F., Fernández-Rouco, N., Carcedo, R.: Educación sexual y ética de las relaciones sexuales y amorosas. Pirámide, Madrid (2017)
40. Osborne, R.: La construcción sexual de la realidad. Cátedra, Madrid (1993)
41. Butler, J.: El género en disputa. El feminismo y la subversión de la identidad. Paidós, México (1990)
42. Córdova, R.: Sexualidades disidentes: entre cuerpos normatizados y cuerpos lábiles. La ventana. Revista de estudios de género **4**(33), 42–72 (2011)
43. Muñoz, M., González, C., Domenech, J., Galindo, L.: Alteraciones Psicológicas de los pacientes con VIH. Grupo Compás, Ecuador (2018)

44. Reyes, M., Domingo, J., Madera, S.R., Carrelo, L.M.: Entre la Razón y la Pasión: La Intimidad Sexual en Parejas Heterosexuales ante la Empresa Preventiva del VIH/SIDA. Qualit. Rep. **12**(4), 658–679 (2007)
45. Cardona-Arias, J.A.: Representaciones sociales de calidad de vida relacionada con la salud en personas con VIH/SIDA, Medellín. Colombia. Revista de Salud Pública **12**, 765–776 (2010)
46. Mora, L.A.: Violencia de pareja en la mujer que vive con VIH. Rev. Colomb. Enferm. **13**(16), 52–63 (2018)
47. Ray, S.: Sexual health for people living with HIV. Reprod. Health Matters **15**, 67–92 (2007)
48. López, F., Fernández-Rouco, N., Carcedo, R.J., Kilani, A., Blázquez, M.I.: La evolución de la sexualidad prepuberal y adolescente: diferencias en afectos y conductas entre varones y mujeres. Cuestiones de género: de la igualdad y la diferencia **5**, 165–184 (2010)
49. Fuertes, A.: Relaciones afectivas y satisfacción sexual en la pareja. Rev. Psicol. Soc. **15**(3), 343–356 (2000)
50. López, F., Del Campo, A., Guijo, V.: Prepuberal sexuality. Eur. J. Medi. Sexol. **12**, 49–65 (2003)
51. Kaida, A., et al.: Sexual inactivity and sexual satisfaction among women living with HIV in Canada in the context of growing social, legal and public health surveillance. J. Int. AIDS Soc. **18**(Suppl 5), 20284 (2015)
52. Schönnesson, L.N., Zeluf, G., García-Huidobro, D., Ross, M.W., Eriksson, L.E., Ekström, A.M.: Sexual (Dis) satisfaction and its contributors among people living with HIV infection in Sweden. Arch. Sex. Behav. **47**(7), 2007–2026 (2018)