

“But I didn’t have the courage to tell”: disclosure of serostatus in the love/sex life of people living with HIV

“Mas não tive coragem de contar”: a revelação da condição sorológica na experiência amorosa de pessoas que vivem com HIV

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Abstract

This article presents a socio-anthropological study, of qualitative approach, that addresses love relationships of people living with HIV/aids (PLWHA) in the current context of infection’s chronicity and discursive restraint on the epidemic. From brief narratives, comments on posts about loving experiences of PLWHA in a personal blog, this study aims to understand the meanings attributed to strategies for serostatus disclosure and the ways of coping with love partners’ reactions facing this attitude. From the thematic analysis of the empirical material, two categories emerged: “but I didn’t have the courage to tell”: the unveiling of the serostatus; and “and all of a sudden disappeared”: the other’s (re) actions in the relationship. The narratives showed the experiences of living with the secret about the own serostatus, and the feelings involved in revealing it when dealing with the possibility of a love relationship. In this sense, the secret is expressed by the lack of “courage to tell” the partner. Moreover, we highlight the meaning attributed to the other’s reaction on knowing about the serostatus, which is mainly distinguished as a “door” that opens up and allows (or not) the love experience.

Keywords: Acquired Immunodeficiency Syndrome; HIV; Illness Experiences; Love; Social Media.

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Resumo

Estudo socioantropológico de abordagem qualitativa que aborda os relacionamentos amorosos de pessoas que vivem com HIV/aids (PVHA) no atual contexto de cronicidade da infecção e de restrição discursiva sobre a epidemia. A partir de narrativas breves em forma de comentários às postagens sobre experiências amorosas de PVHA publicadas em um blog pessoal, este artigo objetiva compreender os significados atribuídos às estratégias para revelação da condição sorológica e as formas de enfrentamento das reações dos parceiros amorosos diante dessa atitude. Da análise temática do material empírico emergiram duas categorias: “mas não tive coragem de contar” - o desvelar da condição sorológica; e “e do nada sumiu” - as (re)ações do outro da relação. As narrativas evidenciaram as experiências na convivência com o segredo em torno de suas condições sorológicas e os sentimentos envolvidos em sua revelação, diante da possibilidade de um relacionamento amoroso. Nesse sentido, o segredo se expressou pela inexistência da “coragem de contar” ao(à) parceiro(a). Além disso, destaca-se o significado atribuído às reações do outro perante o conhecimento da condição sorológica, apontado, principalmente, como uma “porta” que se abre e permite (ou não) a experiência amorosa. **Palavras-chave:** Síndrome de Imunodeficiência Adquirida; HIV; Experiência com a enfermidade; Amor; Mídias sociais.

Introduction

In the early 1980's, the epidemic caused by the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/aids¹) influenced on sexuality and on some ways of living it. Thereby, the epidemic shoved to the public space sexualities and sexual practices regarded as dissident and perverted, since they affronted moral values of the monogamous family, which is nuclear, traditional, heteronormative and procreative (Watney, 1997).

At that time, in the interpretation of the conservative wing of society (notably in the United States of America, where the first infected person was identified), aids arises as a punishment, a reaction to the short sexual liberalization, to contestation arising from May 1968, and to Feminist and Homosexual movements (Camargo Jr., 1995; Watney, 1997; Green, 2000).

In such a context of truth absence about HIV/aids, the discursive production on the subject has grown, especially in general media and in the “scientific race” for explanations, for the guilty and for biomedical technologies able to placate the action of the virus (Daniel; Parker, 1990; Patton, 1990; Camargo Jr., 1995; Czeresnia, 1995; Watney, 1997). Thus, HIV/aids operated in the social imaginary a combat metaphor, already so common in Western medical narratives (Sontag, 1989). On the battlefield, the enemy was clearly defined and carried a “birthmark”: the gay man, nevertheless there were secondary targets, such as sex workers (Patton, 1990).

In this scenario, the sexual panic created around aids spread to the world, producing a social, health and political crisis that interconnected elements such as death (biological and civil), disease, bodily fluids (semen and blood, mostly), sexuality, family, christian morality, medicine, media etc. As a consequence, in the field of social sciences and humanities, the epidemic contributed to advancing studies on sexuality and sexual behavior (Vance, 1995), from the study of the diverse experience

¹ We use the initials “aids” in small letters based on Castilho (1997) argumentation, for whom disease names are common nouns and, therefore, should be written in lowercase letters. Furthermore, it demarcates a critical perspective on the sexual panic created by the epidemic, especially in the 1980s.

facets of people living with HIV/aids (PLWHA). We highlight here some of these productions, without the pretension to be exhaustive in the analysis.

Aids as theme of the day in mass media and the consequential sexual panic were critically analyzed by several authors, in the perspective of such discursive productions being more representative of values and the hegemonic social order than of the biological, epidemiological, psychological and social aspects of aids (Patton, 1990; Watney, 1997; Camargo Jr., 1995; Biancarelli, 1997; Spink et al., 2001; Soares, 1998). The stigma has been discussed in numerous research as a remarkable trait of PLWHA experiences, also the coping and management strategies, such as: keeping the serologic status a secret; selecting people that could know about the condition and act as caregivers; and, among serodiscordant couples, keeping secret about the partner serology to allow the maintenance of familiar, neighboring and work relations (Maksud, 2012; Pollak; Schiltz, 1987; Seffner, 1995; Weitz, 1990; Zukoski; Thorburn, 2009). HIV/aids activism, especially in the epidemic early decades, has exercised a fundamental role in the resignification of seropositive identities, in the construction of biosociality spaces, and, notably, in the political action of non-governmental organizations (NGOs) and associations (Silva, 1999; Valle, 2008; 2015; Pelúcio, 2009; Petrarca; Ribeiro, 2015; Follér, 2010; Barros; Vieira-da-Silva, 2016; Pereira; Nichiata, 2011). The relation between sexuality, homosexuality and HIV/aids was also considerably investigated (Weitz, 1990; Pelúcio; Miskolci, 2009; Guimarães; Terto Jr.; Parker, 1992; Parker, 1997).

With the epidemic “maturity”, other objects have emerged in the scientific production on HIV/aids at social sciences and humanities, namely: the

experience of living with HIV as a long-term condition (Burchardt, 2010; Abadia-Barrero, 2002; Serra et al., 2013; Cunha, 2012). On the other hand, the investigations into sexual practices (such as barebacking²), the use of applications to search for partners, and other forms of sexual scripts proved the subjects’ actions when faced with the risk notion created by the epidemiology and their sexual controlling apparatus³ (Santos, Iriart, 2007; Silva; Iriart, 2010; Hull et al., 2016). As it can be seen, this literature relates to other fields of knowledge (epidemiology, public health, psychology, medicine) in order to understand how the social, economic, cultural and subjective determinants of this epidemic operated.

In this perspective, this article aims to contribute with the debate on socio-anthropological aspects of PLWHA sexual and loving relationships, in the current context of infection chronicity and epidemic discursive restriction. Inácio (2016) denominates epidemic discursive restriction the quenching of aids and HIV in most contemporary cultural discourses - in Literature, Cinema, media in general. He does so by analyzing the social and aesthetic disinterest in the aids thematic since the biomedical and epidemiological strategies increased (medicines, rapid testing, among others) and the virus infection entered the list of long-term suffering and diseases.

It is assumed that, in the last 20 years, a continuous process of positivation of PLWHA is in course, characterized by the displacement of aids as a fatal disease to a not curable, but treatable condition⁴ (Cunha, 2012, emphasis added by the author). In this process, the responsibility to care for the self and the other falls on the person, that is, the imperative adherence to antiretroviral treatment and the

2 According to Silva and Iriart (2010), the term *barebacking* means, literally, *to ride or to mount without cell*, and it started to be used by the gay community (North American) in mid-1990s, analogically, in reference to intentional engagement in sexual practices without the use of condom.

3 The concept of apparatus is presented by Michel Foucault as “a thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philanthropic propositions - in short, the said as much as the unsaid. Such are the elements of the apparatus. The apparatus itself is the system of relations that can be established between these elements” (Foucault, 2010, p. 244).

4 About the term “chronic condition” see the text of Barsagliani (2013). The author tightens the definitions of chronic illness and chronic condition as a way to broaden the understanding of these ways of living determined biological, psychological and/or social situations involving not only the physical body, but also moral values, social support networks and broader social relations (work, school, health services, social security etc.)

adoption of sexual practices considered safe by the health policy - reading, the use of preservatives in sexual relations and the avoiding of dissident practices (Zago; Santos, 2013; Cunha, 2012).

Thus, while the HIV/aids treatment enables quality of living and broader life expectancy, and facilitates to the person the experiencing of this condition in the intimacy of its own body, it can make secrecy and silence the elements around which the HIV/aids experience is built. With such perspective in mind, what is questioned is: how the PLWHA, who maintain (or maintained) their serostatus a secret, produces or signifies (or produced/signified) strategies to reveal it, and which are the ways to confront the reactions of love and/or sexual partners faced with the revealing?

From brief narratives, comments on posts about sexual and loving experiences of PLWHA from the “seropositive”⁵ author in a blog, this article aims to understand the meanings attributed to strategies for serostatus disclosure and the coping ways of sexual and/or love partners’ reactions from this attitude. In this perspective, these narratives acquire a broader dimension because in the (virtual) writing about themselves, the blog followers discursively reconstruct a set of values, representations and social imaginaries of aids that, ultimately, interlace and model the assemblage of those subjects in search for sexual and/or loving relationships.

Methods

This is a qualitative study of documentary type (Prior, 2011), in which the empirical objects were followers’ comments on posts held by the author of a blog on HIV/aids. The choice of such blog is due to the fact that it is one of the leading blogs in Brazil to address the thematic of HIV and to keep regular posts as well as a group of loyal followers. Thus, the blog was understood as a document that provides rich descriptions of practices, customs and social perceptions of the health-disease process as well as the ruptures and continuities in their representations over time (Arruda, 2013).

The blog is also characterized as a public space, and protected by virtual anonymity. This document shows a writing of the self that meets a collective need for knowledge and sharing of experiences among people with similar life conditions.

The blog was organized into four sections: Blog, Articles, Journals and News. We worked with posts on the “Journals” section, between March 2011 (blog creation) and March 2016. In this period, the author wrote 18 posts, distributed as follows: 2011-01; 2013 - 03; 2014 - 05; 2015 - 06; and until March 2016 - 03. The author used pseudonyms such as “Young seropositive” (JS) or “São Paulo teenage” (JP), and claimed to have been born in 1984 and to live with HIV since 2010.

The corpus included visitors’ comments on four of the author’s texts in the blog, which directly addressed the studied subject: “Everything you wanted to know about oral sex but were afraid to ask,” 02/07/2013, 87 comments; “The seropositive dilemma,” 06/18/2015, 172 comments; “Where is the condom?” 07/11/2015, 134 comments; and “Spring and Autumn,” 09/24/2015, 102 comments. For the corpus composition were performed the following steps: 1) identification and location of sources in the blog; 2) filing of the material in electronic format; 3) construction of a material database, holding: title, publication date, number of comments and the text, copied from the blog.

The corpus was analyzed with the thematic coding technique (Flick, 2009) and consisted of: 1) brief description of each JS publication and the respective comments: authorship (JS or visitor), in case of visitors the nickname used, date and identification of central topics; 2) the comments regarding the oldest JS post were deepened to obtain the data codification, based on research theme, objectives and theoretical assumptions; 3) the comments in other publications were analyzed and, subsequently, the meaning units were identified through the grouping of common and unusual codes. In other words, in this step the first stage of interpretation was held, with the meaning units emerging thereafter; and 4) text passages were analyzed, observing more details. When the entire

5 Following convention, we use single quotes for native terms.

corpus was analyzed, we produced a table on which the meaning cores were defined. Finally, based on the meaning cores generated, the thematic categories were constructed.

The ethical aspects established on resolution no. 510/2016, of the National Health Council, were observed. In this type of study, the researcher observes but do not intervene, what sets this as a minimal risk research, since all the information is already published. Besides, the utilized data are of public access, available online at the blog and protected by anonymity. Therefore, it was not possible to socially characterize the visitors. It is worth mentioning that most of the blog followers who had their comments analyzed are living with HIV in secret, which cannot be considered a rule. We also point out that narratives written in the blog, when cited throughout this article, are identified by a fictitious name, randomly chosen by the authors and diverse from the nickname used online.

Results and discussion

After the analysis and interpretation of empirical material, two categories have emerged: 1) “but I didn’t have the courage to tell”: the unveiling of serostatus; and 2) “and all of sudden disappeared”: the other (re)actions on the relationship. The emic content of each one of them is shown below.

“But I didn’t have the courage to tell”: the unveiling of serostatus

This category expresses experiences narrated by the blog visitors on their coexistence with the secret of their serostatus, and the feelings involved in its disclosure facing the possibility of a love relationship. We assumed that such relationships put people in a situation of greater proximity to each other, which may imply intimacy. This, in turn, increase the secrecy tension and produces the temptation of revelation (Simmel, 2009).

In the narratives of PLWHA who visited the blog, the secret was expressed by lack of “courage to tell” people with whom they had close and/or intimate interpersonal relationships. Such experience is molded in a context in which the

history of aids can be divided in “aids from before” and “nowadays aids.” The first was narrated in a catastrophic, near to death way, as written by Helena: “I confess that, when I received the diagnosis, the first person that came to my head was Cazuza... that I would get thinner... bald... people would point me out in the street...”. The “nowadays aids,” on the other hand, praises the achievements of medical knowledge, which had been piling up and allowing increased levels of intervention on clinical and epidemiological reality (Bastos, 2002). This can be observed in Ariel’s report: “(...) HIV became a chronic infection that does not decreases life expectancy and in which the treatment side effects are quite tolerable (...)”. In this perspective, “the contemporaneity made the disease a secret, a horror that installs the silence as form” (Inácio, 2016, p. 498) and that enables to PLWHA to get rid of some negative marks of the “aids from before,” in a continuous movement of positivation of this subjects (Cunha, 2012).

If given this context of “nowadays aids” (Bastos, 2002) the role of PLWHA is the silence, it could be expressed as a strategy of stigma confrontation, according to the blog followers. At the same time, silence could be an obstacle to connecting with another and to live the “forever” in love relationships, from a romantic perspective (Giddens, 1993), as shared by Luiz: “a few days ago, a boy came into my life, but I am really scared of starting a relationship with him because I always think I’m deceiving him, for being hiv+ and not having the courage to tell... I keep putting myself in other people’s place. For example, if I wasn’t positive and someone started a relationship with me and I perchance discovered that the person is hiv+, or even if the person told me that, I probably wouldn’t react well and I believe I’d freak out!”

Given these situations, among the blog regular visitors was common to create strategies to overcome the vicissitudes placed by the secret, for example, the speculation on the other’s reaction. For these subjects, addressing the HIV thematic was a way to probe the impact their secret could have on the other, seeking the acceptance of their condition. From this approach of the HIV theme, PLWHA could feel encouraged or not

to unveil their serostatus. Dominique's account demonstrates how this strategy worked within the relationship: "(...) during a telephone conversation, I discussed the HIV theme, the treatments evolution, the serodiscordance among couples and numerous other things that are no longer as it was in the 1980s and 1990s. He demonstrated to be curious, interested and surprised with the medicine advancement. However, he revealed that if he had HIV he would rather die than live with it [the virus]. This words sounded EXTREMELY DISTURBING in my head, then I diverted the subject slowly. I've thought about it... But I didn't have the courage to tell."

This kind of experiences have been related in studies that analyze the serologic status disclosure in romantic and sexual relationships between serodiscordant people. In these circumstances, PLWHA fear that the unveiling of their serostatus can "kill the mood" of the relationship and, depending on the other's reaction, the revelation can bring to the affective and sexual scenario undesired mementos of disease and death (the "aids from before") (Carballo-Diéguez et al., 2006). "With the passing of the days I took forward a relationship without acceptance expectations, and decided to broke up out of nowhere. I still have feelings for him and I realize is reciprocal. But facing that, I don't want to suffer" (Dominique). Thus, these influences would be able to turn an affective relationship into a contractual one, with expiry date, given the lack of expectation of serostatus acceptance by the partner: "recently I got involved with a seronegative guy. I didn't get to tell him about my seropositivity, but I mean to do it, I always have. It was a 40-day entanglement, intense, with harmony; and everything lead me to think that it would be nice to tell him. We had sex already, always with a condom" (Luiza).

As it can be observed in the previous narratives, "nowadays aids" allowed to PLWHA distinct assemblages of those that marked the disease experience in the epidemic beginning, since it facilitates the right to secrecy. But, at the same time, it inserts these subjects in a secret world and an official world (Simmel, 2009). In this case, the first involves the private, individual and intimate

dimension of those who live with HIV and/or their nearest social support network; the latter concerns the public, social and international dimension, in which the subject maintains a personal seronegativity facade. That is, the PLWHA can make use of strategies in everyday life to navigate between these two worlds, to keep consistency between representation elements: role, performance, personal facade, expressive control etc. (Goffman, 2011). Besides, we highlight these worlds and representations are not opposed or dichotomized. What do exists is imbrication, overlaps, coexistence and capillarity.

It is important to note that a considerable part of the blog followers lived this condition in secret, but this is not a compulsory rule. Studies developed with NGOs on HIV/aids in Rio de Janeiro showed that the political and social engagement of PLWHA in these organizations allowed subjectification processes, in which protagonism and activism stood as vectors of self-transformation, rupturing with narratives marked by suffering, fear, stigmatization and silencing (Pelúcio, 2009; Valle, 2008).

On the other hand, the secret world introduces a contradiction in living the HIV condition as a "chronic infection." The contemporary restraint of discourses on the disease (Inácio, 2016) brings up symbolic dimensions described as civil death by activists of the social HIV/aids movement, mainly in the 1980's (Daniel, 1989). Today this civil death updates to secret disease, implying a new form of symbolic death

since people no longer die of HIV, they continue to die in the silence of the impossibility to reveal the serostatus, in the rejection from a public exposure that would involve death of affection, and even yet in aspects such as shame, silencing, abandonment, although there are effective treatments today" (Inácio, 2016, p. 498-9).

It is in this scenario that the loving relationships assume a contractual version, in which the main clauses are expressed according to the blog followers: "I do the antiretroviral treatment, I'm undetectable and avoid oral sex" (Luisa); "I

preserve myself, I always use condom and do my treatment, I'm undetectable" (Pedro).

Finally, the revelation or not of the secret conforms a dilemma for PLWHA, as discussed in the post "The seropositive dilemma," written by JS. The narratives produced on the 172 comments of this publication, and in other posts, demonstrated the creative action and the feelings present in the experience of those that purport to live a romantic relationship. There is, yet, another form of acting, generally experienced in the initial period of living with HIV: to abstain, since not having a relationship in this context implies in not needing to "deal" with the secret. Thus, as in an equation, not to "deal" with the secret might result in not feeling tempted to reveal it; not to reveal leads to not suffering with the other's reaction, but, on the other hand, to abstain from living the love experience. "I don't have the courage to tell who I know, I haven't had sex with anyone yet. Despite always wanting things like a serious relationship, marriage and to build a family" (Henriqueta).

"And all of a sudden disappeared": the other's (re)actions in the relationship

In this category are highlighted the experiences of blog followers facing the other's reaction due to knowledge of serostatus. Generally, the analyzed comments point to such reactions mainly as a "door" that opens up and allows (or not) the love experience. We signalize that the discussion of empirical material will be done based on a sociology of love and intimacy (Giddens, 1993; Bauman, 2004), which, saved their theoretical differences, allow to understand the context of contemporary relationships where the blog followers search for partnerships and sexual and/or love relationships

It is assumed that these searches take place in a society characterized by the frailty of human bonds, by the insecurity it inspires, and by the conflicting desires of tightening bonds and keeping them loose at the same time (Bauman, 2004), as

Lúcio reported: "I believe in romantic love and hope to, as well as the young positive, find someone. PS: young positive, I know u [you] are heterosexual, what a pity! But would it be possible to create a link here at the site for us to meet people for a serious relationship instead of casual sex?". Besides, we highlight a set of social transformations involving sexuality, love and eroticism that have been developing and contrasting (or not) the ideal of romantic love (Giddens, 1993), as exemplified by Jefferson's narrative: "the only thing I wanted in my life was going back to loving and being loved, but the way things evolved, each day I have less hope of having a happy life. I wish I could overcome this, rediscover love, rediscover the meaning of life."

Given this context and the interpretation of the material published in the blog, we understand that, on the one hand, there is no fundamental difference in the love life of PLWHA that diverges radically from the experience of seronegative people; on the other hand, the HIV produces folds⁶ in the relationship ground, which needs some elaboration - as related by Pedro: "since the diagnose, this has always been my doubt: to tell or not to tell?".

These folds are composed by two sides. The first side is constituted by the tension of secrecy and the revelation temptation as the interpersonal contact increases (Simmel, 2009), according to what was seen in the previous category. Here there can be a moment of choosing and deciding, which consists of "to tell or not tell," guided by criteria of quantitative (relationship extent, for example) and qualitative (affection nature, involvement degree, intimacy etc.) type.

For some of the blog followers who were in the initial phase of affection and/or sexual relationships, the unveiling of serostatus was not deemed necessary, considered the right to privacy: "if I'm okay and undetectable, there is no reason to reveal something so intimate in a first, second or even a third date" (Pedro). For others, faced with the prospect of a "love relationship" that awaken feelings of security, trust and stability, in other words:

⁶ We use here the metaphor "fold" to allude the contingencies posed by HIV in the love and sexual experience, in the extent that it tensions the romantically idealized encounters and relationships. It refers, therefore, to situations and events related to serostatus disclosure that stand out and disturb the everyday routine of this people's loving and sexual relationships.

not a top-pocket relationship (Bauman, 2004), the PLWHA might feel tempted and driven to unveiling the secret, as can be observed in the following comments: “when the situation evolves to a romantic relationship it becomes even harder. I don’t know if I could have sex with someone without telling” (Giovane); “If [I] notice a possible romantic involvement, the picture changes: to reveal the positive serology becomes a matter of confidence in the partner” (Pedro); ‘I told my boyfriend because I acquired a confidence, a huge attachment, a love that grows every second” (Rebeca).

The other side of the fold can be considered the possible reaction camp of the other, after the secret is revealed. Generally speaking, in the material published at the blog people reported the end of the relationship as the most recurrent event, that can happen in the following ways: disappearing (“I was traumatized, because the person was dying of love for me, said that loved me and couldn’t live without me... And all of the sudden disappeared!” - Heitor), claiming to have other reasons to end the relationship (“I got dumped and my world collapsed. Of course, he swore that it was for another reason, but I know it has everything to do with my health condition” - Noah), not keeping contact, sending the PLWHA away, changing telephone numbers and electronic addresses (“I took [the other] to do the test, knowing it was going to be negative, because I was never exposed with him. Since then, he told me to disappear, changed the phone numbers, e-mails, and never contacted me again...” - Marcela). These rejection experiences were reported mainly in the following JS posts: “Spring and Autumn” and “The seropositive dilemma.”

These narratives confirm the factors that influence the partner to react in rejection of the PLWHA after disclosure of serostatus. Such factors were identified in a study conducted in South Africa, and consist of: fear of discrimination; lack of information about HIV transmission and protection; a desire to protect the self, and not to be

stigmatized (Simbayi et al., 2007). In this possibility horizon, the process of unveiling the serostatus becomes quite stressful and stressful, even in cases with positive outcomes. distressing, causing some subjects to relive the moment of diagnosis: “Look, fella,, this month I lived the experience of telling a lad I was hopelessly in love with! And it is pretty much this: to live the day of diagnosis again!” (Marcela).

On the other hand, many followers’ comments describe experiences of partner acceptance after revelation of the secret. In these situations, the love was pointed as largely responsible for the overcoming of HIV stigma and for provoking feelings of understanding and acceptance. These reactions are seen as demonstrations of affection/love (“love proof”) by the other in the relationship. “It’s an angel who came into my life at the right moment, after so many failed attempts! Only love is capable of breaking those barriers!” (Vanessa). “(...) I’ve already woke up with him crying of worry for me and, sometimes, I still wonder if I want any love proofs... I always say that he already gave me the greatest love proof just by being with me” (Bruna).

In this conception, those subjects’ experiences ended up being much more marked by the strength of affective linkage and the emotional security than for the stigmata. In an ethnography held with members of an NGO on HIV/aids in Rio de Janeiro, other assemblages of PLWHA were described in the search for partners. In that context, the coexistence with people who shared a common clinical identity (or not, since this was not a sine qua non condition to participate in the NGO) normally facilitated, at least in the beginning, the sexual contacts and affective searches. However, other social difference markers as social class, color/race, gender and sexual orientation used to guide the social interaction on that space, which could be considered a “micro-physical market”⁷ specialized in possible sexual encounters and partnerships (Valle, 2008).

7 Valle (2008, p. 680) uses the expression “micro-physical market” referring to the social world shared by the HIV/aids NGO members he studied. This market comprised a specialized relational space, in which it was possible for sexual encounters and partnerships to happen without incurring, at first sight, in prejudice and stigmatizing acts. After all, the coexistence principle among the author’s studied interlocutors was solidarity.

Thus, in the comments by blog followers, people with whom they had relationships come to express character qualities regarded as “unique” and “special,” even more for being individuals with negative serologic status, as can be observed in Carlos’ testimony: “(...)it seems that when we mature, life starts to erect longer, higher walls and to offer harder obstacles, for you to demonstrate yourself able in your love purpose, for you to show yourself that ‘I love you’ is not just an emotional speech pronounced to the other person. For now we call ourselves a serodiscordant couple, but our level of concordance, our viral load of affection is very high, and our incompatibility CD4, low. We have a diagnosis to envy many couples. We are completely infected by love and intend never to be cured!”

On the exposed facts, it should be highlighted that the search for partners and relationship involvements, reported by the blog followers, is enrolled in the broader context of contemporary social relations (Giddens, 1993; Bauman, 2004), as previously noted. The reports in commentary form, following the JS posts, are in some measure about this necessity to create safer, lasting and stable bonds. Perhaps this necessity grows for the person living with HIV, considering this is a condition in which stigma and prejudices fall, directly, on what is most intimate: their sexuality and sexual practices or, even, their ways to orgasm.

However, as evidenced in the previous category, the experience of those who purport to live a love relationship is marked by uncertainty, which is common to any human being (independent of HIV). This because relationships can be, in the same extent, the shelter against solitude, frailty and insecurity; and the greenhouse where these feelings grow and develop (Bauman, 2004).

Final remarks

Our research sought to understand the meanings attributed to strategies for serostatus disclosure, and the ways of coping with reactions of love and/or sexual partners after this revelation. Thus, the blog proved to be an instance for production of senses and meanings concerning HIV experiences and, particularly, sexual and/or affection practices

before situations in which the unveiling of serologic status to potential partners is considered necessary. In this process, the research with/about social media contributed to the study of disease and long-term suffering experiences, since it happened on a space in which people could discursively reconstruct the values, representations, experiences and social imaginaries about a condition, in this case the HIV/aids, from their assemblies in day-to-day universe.

This study made it possible to seize the revelation, or not, of secrecy as a dilemma for PLWHA; the creative action and the feelings present in the experience of those subjects who purport to live a romantic relationship. At the same time, another form of acting from the blog followers, especially in the first period of living with HIV: the non-involvement in romantic and/or sexual relationships, which are usually marked by the proximity and intimacy with other. They are, therefore, coping strategies of stigmatizing experiences and of emotional and social suffering.

Given this context, diagnosis, affection, sex, intimacy, and HIV intertwine, producing diverse effects in self-care, safety on sexual practices, identity, and building of new sexual and/or romantic relationships. Moreover, we highlight the meaning attributed to the other’s reaction after knowing about the serostatus, which is mainly pointed as a “door” that opens up and allows (or not) the love experience.

In addition, it is understandable that HIV seropositivity may or may not constitute an obstacle to these love and sexual experiences, depending on each subject biography, on the singularity of their experiences, and on their positions and insertions in the social webs. Finally, we must highlight the limitations imposed by the impossibility of contextualizing the narratives of the blog followers using social difference markers (generation, gender, sexual orientation, race/ethnicity, social class) as well as to point out the singularities and implications that these raise. It is noteworthy that these aspects require theoretical and methodological deepening, pointing to the need for new studies on the subject of social media. Despite this, the narratives produced a virtual space for the sharing of experiences, marked by the construction of mutual help relations and by biosociality.

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Authors' contribution

Borges developed the research, analyzed data and wrote the article. Silva revised, corrected, and suggested changes in the manuscript. Melo advised the research and revised, corrected, and suggested changes in the manuscript.

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