

Internet and hiv/aids: a virtual ethnography on Facebook

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Internet y VIH/SIDA: una etnografía virtual en Facebook (resumen: p. 15)

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This paper identified and analyzed some interactions on the internet in the daily of people living with HIV and AIDS (PLHA) in Brazil. As methods we made interviews with PLHA analyzed by content analysis and a virtual ethnography of a secret group of PLHA on Facebook. These are the following results: sociability produced in the internet helps to reduce suffering in relation to prejudice; there are not many welcoming zones for PLHA on the internet; PLHA linked to social networks have more encouragement to not give up the medication; negotiations about medication and symptoms take place in social networks. We conclude that there is a need to have welcoming zones to PLHA on the internet guaranteed by public policy; medical education needs to cover issues related to the internet and health.

Keywords: Communication and health. Internet and health. HIV/AIDS. Sociology of the internet. Virtual ethnography.

Introduction

In October 2017, around 120 million Brazilians had internet access. Brazil has ranked fourth in relation to the number of internet users worldwide, after China, India and USA¹. However, despite the advances, the proportion of households of poor families with internet was 23%².

As the community of Internet users grows, how do people living with HIV/AIDS (PLHA) in Brazil interpret the multiple information on health from the various sources in the virtual world?

The prevalence and incidence of HIV among young individuals has been increasing in Brazil, especially among men who have sexual intercourse with other men (MSM). Between the ages of 15 and 19 years, for example, the prevalence tripled between 2006 and 2015³. On another hand, the seropositivity is increasingly regarded as a chronic disease⁴.

One of the most prominent social movements devoted to public health issues in Brazil relates to PLHA due to its importance in the establishment of patient rights and in the formulation of public policies since the early eighties^{5,6}. The repercussions of this activism in the Internet are inevitable and make it necessary to analyze the associated personal experiences.

Studying the narratives of PLHA on the internet is fundamental for understanding the rhetoric, addressing cultural differences and assisting in the global response against the epidemic⁷. Brazil is one of the pioneers in this response.

Methods

The present study was empirical, with qualitative analysis, using the methods of content analysis and virtual ethnography.

The field of research covered a secret group on Facebook called the National Network of People Living or Living Together with HIV/AIDS (RNPVCHA) and PLHA who were connected to support group (COMVIDA group) and social movements: Rio de Janeiro Pela Vidda group, Niterói Pela Vidda group, National Network of People Living with HIV/AIDS and National Network of Adolescents and Young People Living with HIV/AIDS (RNAJVHA).

Content analysis

All 19 interviews were semi-structured and were conducted in depth, with a mean duration of 40 minutes. They were analyzed by means of theme analysis⁸. All the participants were PLHA, and they duly agree to take part through signing a free and informed consent statement. This research was approved by Brazilian National Health Council of Ethics in Research with protocol number 14009213.4.0000.5260.

The composition of the interview group was as follows: 3 were women; 7 were connected to the support group COMVIDA, 10 worked in social movements; 7 were bloggers and also activists in social movements. For privacy reasons, all interviewees are referred by "A", followed by a number reflecting the chronological order of the interview analysis.

Virtual ethnography

Virtual ethnography comes from debates at the end of the 20th century on the subject of research methodology on the internet. Hine⁹ proposed a theoretical-methodological point of departure: Sociology of Cyber-Social-Scientific Knowledge, in which the Internet has both a cultural context and a metanalytic technological context, for being a device.

The classical ethnography works with a limited physical space and time, the notion in virtual ethnography, and all the techniques of the so-called digital anthropology, brings to the field a challenge of a new mediation between subjects and collectives, presenting other definitions in space-time, while maintaining the objective of cultural interpretation of a particular community, in this case, virtual^{10,11}.

Using an ethnographic field diary, the following blogs and websites were analyzed with the aim of selecting one for ethnographic research: Facing feminization of AIDS and STD in RJ; Mara Moreira – Woman living with HIV/AIDS; Activism against AIDS/TB; Viral load; Renato da Matta; Diary of the Second Closet: young, gay and living with HIV/AIDS; Diary of a Seropositive Young Person; Radar: connecting lives; Pleasure to meet you, I am Alexandre; RNAJVHA and RNPVCHA. RNPVCHA was chosen for performing the virtual ethnography analysis for the following reasons:

- . It is a closed group, in which, in theory, people will be more open to discussing their conditions relating to HIV/AIDS;
- . It is a group on Facebook, a social network that, in 2014 in Brazil, had 59 million accesses every day ;
- . Use of devices that already exist on Facebook: message notification, posts and tags;
- . The group began in 2013 and has had an exponential increase in membership: in June 2014, there were 475 members, in January 2015, 810; and in March 2017, 1773.

On August 18, 2014, through using a post from one of the group moderators, I introduced myself and presented the objectives of this research to all members. I was cleared by the group to begin the ethnographic analysis. This was done between September 2014 and January 2015. The analysis was divided into: discrimination/prejudice and medicalization. The individuals who underwent ethnographic assessment were named with the prefix letter “E”, and the numbering that followed was in the chronological order of the ethnographic analysis.

Results

Virtual ethnography

Discrimination and prejudice: double stigma

There are numerous posts regarding the tension of telling relatives and spouses, or not telling them, about the condition of living with HIV. Besides the virus itself, there is the matter of prejudice in relation to the AIDS-homosexuality binomial, thus producing double stigma¹².



[...] On Friday I admitted being gay to my family. As a result of my confession, my parents, who are extremely catholic and traditional, treated me as if I were ill, called me a disgrace to the family and said they would rather have died than know about this. They took me to see a psychologist. [...] they cut all my financial support for my studies [...] (E1, 2014)

Silence is an important strategy against prejudice for PLHA¹³. Seropositive homosexual young people have difficulty in telling the truth to their parents, whereas it is more common to share this information with a partner, sibling and friends¹⁴.

E4 spoke about the difficulty in admitting his sexuality to his parents that he had faced during adolescence, and also revealed that he had attempted suicide: “[...] when I was 16 or 17 years old I often wished to die and even tried to commit suicide because of my fear of telling people that I liked men [...]” (E4, 2014).

The risk that an LGBT person might commit suicide is significantly higher than that of a heterosexual person, with percentages of 21.5% vs. 4.2%, respectively. Among the LGBT teenage population, that is deprived of an environment of emotional support, the risk of suicide attempts is 20% higher than in an environment with support¹⁵.

Just like the dilemma of whether to admit to being gay or not, whether to tell about HIV or not was a recurring theme in the group, which made it a welcoming space.

I met someone, and it's nothing serious YET, but we decided to get to know each other more to see if this goes from casual to serious commitment. Do you think I should tell him about my serology now, at the beginning or not? (E3, 2014)

E5 (2014) responded, showing trust in the confidentiality of the RNPVCHA: “Yeah... I have been seropositive for 8 years now and still haven't told my family.” Trust in confidentiality among the members and Facebook's privacy technology is curiously unwavering. Despite the general distrust that exists in relation to the internet, people share very intimate secrets that they have been keeping for years.

Besides telling spouses and family, there is also drama related to informing healthcare professionals or not. E7's question (2014) generated 38 comments, which is a lot compared to the average number of comments in group posts: “When you go to the emergency room (ER) and the doctor asks if you have any disease, do you have to mention HIV?”

E8 (2014) commented: “I never tell them! [...] I choose not to tell them because it's an ER close to my home and information could leak somehow. I already get treatment in another city because this.” E9 (2014), on the other hand, made a dangerous comment: “I don't believe it's important, unless I consider that my symptoms [in that occasion] are related to HIV.” The danger lies in how he can be sure that his symptoms on that occasion were or were not related to HIV. E13 was the only one to point out this matter:

[...] and what if the professional had an accident with a needle that he used on you? Prophylaxis for this person should be done on the spot [...] Some people



said, “only if I think it has something to do with the virus”... Really? You mean everyone is getting to know well all the possible reactions a viral infection can cause...? Especially HIV? A highly mutational virus! (E13, 2014)

Much of the silence that E8 and E9 chose to follow helped to avoid the embarrassment suffered by E10:

I was at a private ER when the assistant nurse was about to pierce me without gloves. I asked her to put a pair of gloves on and she said it wasn't necessary... I then told her I had HIV. Man... The look on her face was priceless. She ran, got gloves and kept whispering about it to other nurses... (E10, 2014)

Women have concern with regard to admitting to having HIV at primary healthcare services. Regardless of their health situation, these women only revealed their diagnosis after feeling safe and well connected to the professional¹⁶.

This is a matter also for health municipal managers who try to decentralize the HIV/AIDS care flow. Given that community health-care agents usually live in the same neighbourhood of their workplace, many people avoid mentioning the subject at a service close to home¹⁷.

Some interviewees also reported experiencing discrimination and unpreparedness among healthcare professionals. A3 said that his diagnosis of HIV was delayed and was questioned, due to the following conversation that he had had with his physician: “Come on, can't this be HIV?” “No, are you fag?” “No.” “Then, forget it.” (A3, 2014)

A11 commented on the lack of preparedness of physicians in general when bringing news regarding a diagnosis of HIV:

I was examined by a private-practice dermatologist and he was completely unprepared to deliver this kind of information [...] he held my arm and said: “There is a suspicion of HIV, but don't worry because you can live well and even play soccer.” He said that! If I had had a ball, I would have thrown it at his head! I went to the square, had a smoke and cried. Desperately. (A11, 2014)

Medicalization: “it is all a matter of opinion”

Members of the group advised on what to do in a case of decreasing CD4 cells, growing viral load (VL) and symptoms of dermatological manifestations, shown in photos. E14 (2014) reported: “I am super concerned with my CD4 of 271 mm³. Although my VL has reduced significantly, the anguish remains.”

E15 (2014) replied: “My advice to everyone is to get genotyping done”. E16 (2014) also advised: “taking Sustagen helps”.

One interview mentioned alternative medicine: “Yesterday I joined a [chatroom] about arthrosis and they were talking about the white and black *sucupira* [*Pterodon emarginatus*] seed [...] (A10, 2014).

Alternative or complementary medicine has already been discussed from the point of view of medicalization, in the sense that the condition of being alternative does not prevent it from being less medicalizing^{18,19}.

There was a more dangerous case relating to hemotherapy. In the same post mentioned previously, E18 (2014) recommended: “[...] physical therapy methods (auto-hemotherapy and others)”. E19 reported a negative experience with this procedure:

[...] I regreted joining another group: I did everything I was told to do, but I realized that I was killing myself. I had stopped taking retrovirals to begin hemotherapy [...] many friends alerted me about what I was doing. Today I am back taking my retroviral medication. (E19, 2015)

There are risks to health to which PLHA accessing the internet are exposed²⁰. All of the 10 comments to this post encouraged him to go back to taking his medication and staying in RNPCVHA.

The greatest challenge for any patient with a chronic condition is to understand why it is necessary to take medication for the rest of their lives, even if they feel good. The social representation that each individual uses to adhere to medication is generally multifactorial²¹.

Questions about medications and their effects, types, times to take them and associations with other medications were also frequently asked in the group:

I have an urgent question. A friend is doing post-exposure prophylaxis. He takes tenofovir every 24 hours (20:30) and lamivudine + zidovudine every 12 hours (8:30 and 20:30). Today, he accidentally took an extra dose of tenofovir at 8:30, with lamivudine + zidovudine. Should he not take the 20:30 dose today or should he keep on taking it as usual? (E20, 2015)

The initial replies gave divergent advice. E21 (2015) replied: “Ignore the dose already taken and continue with the same daily scheme. [...]” E22 (2015) suggested another course: “It is best not to take the medication at 20:30 to avoid a high dosage, and tomorrow he can restart the scheme he was using before.” On the other hand, E23 (2015) gave more details in his comment:

If your friend doesn't have any renal issues, he can take tenofovir again without problem, since it will be eliminated through his urine anyway [...] if it were me, I would take it only on the next day! He can get the dose right again, a delay of a couple of hours per day until he is back on track. “After all, it's all a matter of opinion”. (E23, 2015)

The relativization that E23 mentions highlights the current scenario of an infinity of information available. This is advantageous for people who are able to filter the content, but it becomes a perfect scenario enabling the medical-industrial complex to deliberately distort science through inventing doubts and fake truths^{22,23}.

The author of the post found the information confusing and replied humorously: “Thanks for the help, guys, but we have 3 comments indicating 3 different things. Help! hahaha” (E20, 2014).

Analysis of interview content

Reliability of the internet

Although there is greater availability of information on the internet, some activists regarding HIV/AIDS have excessive and dangerous confidence in their experience and in their own quality criteria: “I feel very empowered regarding the issue of diseases and I know how much of it [on the internet] is true or not.” (A5, 2013).

When A9 was questioned about the criteria he chose to trust, he answered: “my own experiences, those of my friends and those of my group.”

On the other hand, A8 highlighted that what made him suspicious of found information in the internet was the standard of language: “First of all the language, because the number of people writing incorrectly is ever bigger these days.”

There is evidence that people with HIV look for more knowledge to ground their decisions, thus decreasing the conflict at the time of choosing²⁴.

In relation to communication and health, some studies conducted in Brazil have shown that the media influences people’s decisions²⁵⁻²⁷.

Because of stimulation from the media to abandon medication, A16 spent 10 years without using his medication. It was a story on the internet in a monthly American magazine, *Esquire*, in 1999. The content mentioned the possibility of interrupting medication, through a hypothesis without scientific evidence.

A18 trusted information more when a doctor signed the statement: “if it is from a medical association and it has something written that proves that it is really coming from a doctor, this gives a bit more trust.” This corroborates the trust in experts displayed by internet users²⁸.

However, there are many websites signed by doctors that are financed by companies, thus making it difficult to establish whether there might be conflicts of interest.

A17 admitted that, in discussion forums such as FONAIDS, the level of the debate became higher when clinical trial results were shared, as happened recently with the drug Truvada for pre-exposure. However, A17 mentioned that there was difficulty, even among researchers, in evaluating clinical trials: “Designing a clinical trial is a complex business, isn’t it?”

Taking the internet when seeing a doctor

The criticisms regarding imposition of medical normativization and the discredited power relationship between patient and physician are already known^{29,30}. On the other hand, the opposite, i.e. an unfavorable power relationship for the physician, may be one of the new issues ensuing from the appearance of expert patients.

When [the doctor] gave me the prescription, I said: “No, this medication is no longer in production; it doesn’t exist! [...] There is a new recommendation. I’ve seen it in the internet”. (A16, 2014)

There is also depreciation of the doctor's capacity to link the content from articles to his clinical experience for addressing a given patient's singular and specific case.

[...] I've started to become a tedious person because I directly research what is going on with me [...] "Doctor, I have this here." "How do you know?" "It's here! Are you going to argue with me?" (A4, 2013)

Aspects of medical misconduct as arrogance, omnipotence and authoritarianism have a historical-social-epistemological basis grounded in the monopoly of biomedical healing³¹. However, in analyzing these narratives, we found that the same practices were being used by patients.

Much of this arrogance from patients is a reaction towards the sparse explanations that physicians provide to patients during their consultations³².

A17 maintained that he searched for information on health online especially when doctors did not explain things well.

I had a resonance done [...] "can you show me where the injury is?" "I fit you in and you want me to teach you about MRI examinations?" [said the doctor, in an uninterested manner, and he continued]: "Ah, it's here, do you see?" If he had explained this, taking a bit more time and a bit more effort... [...] this is what the internet is for: giving us the same horizon... (A17, 2014)

One of the main points is exactly this: the same variety of information on health is available on the internet through researched both by physicians and by patients, but this does not provide a horizon of knowledge between them. The hermeneutical process of meanings ascribed to the object differs between them, not only because one is the doctor and the other is the patient, but also because they are different subjects, each with their own language and codes.

The benefit of this mediation may surmount the individual level and involve the collective group. A14's case symbolizes how the internet search and information sharing with the doctor can generate important social products.

Through the internet, I heard that there was a medication outside of Brazil that I could be using [he was suffering from therapeutic failure]. I said it to my doctor and she created a research project [...] today, in Rio, there are 5 other people benefiting from this medication. (A14, 2013)

A14 is also a blogger, and this achievement was shared so that other people would be encouraged to demand it from the healthcare services and research centers in their towns.

Virtual reception: care at a distance

Social support provided by the digital world to PLHA at a time before the boom of social networks was already significant³³. In fact, there is no guarantee that face-to-face encounters would always be satisfying for PLHA.



One girl said: “There is a group that is cool.” I went, but I would go in a bad state and would come out worse. This group was not about medication, only about “nature”... “Forget viral load.” I left feeling so bad, man, so bad (A15, 2014)

After several diseases due to HIV, A8 went into depression. He admitted that the internet helped him.

My brother said: “You need this here.” He gave me a computer with internet. I looked at it with suspicious, but later... Chat room? Sex? Great! If I don’t do it in real life, I can do it here. [...] on UOL [chat room] I saw: “Various”. What’s in here? Boom! “HIV” came up. It radically transformed my life... (A8, 2014)

The solitude of PLHA has been evaluated as an intrinsic component of the stigma of HIV, especially in vulnerable groups, such as elderly people, women and MSM³⁴.

A11 also had great experiences with the internet, regarding sociability and virtual reception.

The internet was the main space for elaborating the experience of living with HIV, after 3 months of awareness of my condition, I began to write in a blog. [...] Each person has a strategy for how to conceptualize and deal with a discovery of this magnitude, and blogging was essential for me (A11, 2014)

It is already described the benefit of the use of blogs among people suffering from psychiatric disorders³⁵. One study analyzed the relationship between readers of HIV blogs and readers of HIV institutional websites, and they pointed out that the first have a more positive attitude in relation to preventive measures³⁶.

e-activists

I am frail; I can barely move, but I have nearly 5,000 people on my profile [Facebook]. There is a simulator to see the ranking, and I am the fourth most influential person in my town. I mean, my social network has mayors, councillors and politicians, there is a very rich life as an activist through Facebook (A8, 2014)

It is important to point out one characteristic of the PLHA activism: the production of what could be called “lay expertise” which was present decades before the internet. HIV/AIDS militants have come a long way to reach recognition from research centers who designed clinical trials to investigate the effect of precursor medications³⁷.

A7 was enthusiastic about the formation of networks between PLHA that the internet can produce:

[...] virtual militancy can gain space that simply cannot be achieved through physical militancy. I can reach people who live in Portugal, France, Mozambique

and Germany. I don't need to schedule a meeting and spend a fortune on a national meeting to gather all these people together (A7, 2014)

A16 is part of the Media Ninja, and participated in the coverage of the demonstrations in Brazil in 2013 by camping out in front of the house of the former governor of Rio de Janeiro, Sérgio Cabral. "I basically represented the AIDS movement in all demonstrations in Rio".

Media Ninja is a group that began in March 2013 and aims to clarify that "the old intermediaries are in no condition to acknowledge the new". It has connections with alternative medias involved in the Arab Spring and in Occupy Wall Street.

Besides these actions, he used this media in healthcare centers to denounce lack of medication and infrastructure:

I use Media Ninja a lot when I go to healthcare units that don't have acyclovir, Bactrim [trimethoprim/sulfamethoxazole] or ranitidine [...] On the spot, I can turn on my phone, report and start coverage. On this Media Ninja on my profile [on Twitter], for example, I have Queiroz, at Record [a journalist], I have secretaries, advisors... [...] I have around 5,000 followers across Brazil (A16, 2014)

Being a member of the HIV/AIDS commission of the State Health Council of Rio de Janeiro and the National Health Council, A16 uses material and interviews that he produces to put pressure on the public authorities: "I send this to ministers, state secretaries, municipal secretaries and even to Dilma [ex-president]. There is a large repercussion; decisions are made immediately, and it is a very powerful weapon."

Discussion

From the virtual ethnography, some points can be raised:

- 1) The level of trust goes beyond what would be expected regarding confidentiality, both between members and with Facebook itself;
- 2) RNPVCHA serves as a support network for people to unburden themselves, ask questions regarding medication and symptoms, have affective encounters and search for knowledge about new developments in the HIV/AIDS world;
- 3) In the posts about doubts, medication was the most frequent topic;
- 4) Advice regarding medicine is often banalized, there is omission and distortion of information;
- 5) Healthcare professionals are unprepared to approach PLHA;
- 6) The greatest influence in the group, besides moderators, are key people who post more frequently, or others who, even if not posting much, are very well respected due to their long experience with HIV/AIDS and are seen as models of hope for the group;
- 7) Few women are active in the group, which is formed mostly by homosexual men. Nonetheless, there is no discrimination against heterosexual individuals.

Finally, it is clear that the success of the RNPVCHA is due to the immense lack of such support and discussions on prevention, stigma, medication, adherence to medication and sexuality. The fact that the health services are very involved with diagnosis and treatment, together with the crises in the most social movements, led to a gap in the care mechanisms that came to be partially filled by “non-institutional” initiatives.

This ethnographic picture shows there are some reasons for going to the internet. Among these, the two main reasons are to seek a comfortable space, free from stigma, where confidentialities and stories of discrimination can be exchanged; and to fulfill the need to know about the use and effects of medications, beyond what is said by doctors. A lot of information is given value without the need for credentials, diplomas or scientific stamps of approval. Personal experiences are enough. The problem is that these experiences are not obtained in isolation and are socially constructed through elements that, among others, include science itself intertwined with medicalization process.

According Joint United Nations Programme on HIV/AIDS and Joint United Nations Programme on HIV/Aids, the goal in the HIV/AIDS field among member countries for the year 2030 is the so-called 90-90-90 target: 90% of the population tested, 90% of seropositive people with treatment started and 90% of these with viral load brought down to zero³⁸.

In Brazil, the number of people who are aware of being seropositive but are not undergoing treatment is approximately twice the estimated number of HIV-positive people who have not yet been tested. The effort needed to achieve the goal set by the United Nations will certainly require great investment in social media and blogs by the government and its agencies and by social movements. Beyond the economic investments, the debate will take place on the networks, in every post and in every comment.

The epidemiological situation in Brazil is a matter for concern, not because of a lack of antiretroviral medication and condoms in public healthcare services, but because of the following factors: the disease has become a banal matter among a generation that did not live through the drama of its first years; the epidemic has reached a less favored economic class, in which addition of yet another disease among all the others has not provoked the combative reaction needed; and the federal government has retreated from efforts regarding HIV/AIDS policies, especially in the field of prevention.

In the light of the shattering of traditional HIV/AIDS social movements, investment in political formation among the young seropositive population has become an urgent matter. Unfortunately, this population has been increasing within the Brazilian epidemiology scenario, especially among male homosexuals. The current scenario in Brazil is one of resurgence of a more devastating epidemic, together with absence of resources. A search for creative solutions for the young population is needed. Public financing for health promotion projects aiming to decrease disease transmission in this age group should be mostly focused on social media³⁹.

One of the moderators of RNPVCHA stated in an interview that he had created this group because he was bothered by the absence of virtual PLHA care spaces, the ones that existed were basically meant to enable and stimulate political struggles



around HIV / AIDS in the country. According to the moderator, he and others were interested in “a more self-militant” (A7, 2014)

Although “self-militancy” seems semantic incoherence, the construction of autonomous care networks, specifically RNPVCHA, not necessarily linked to public policies, can precisely stimulate similar networks through public policies, in order to increase care and adherence to medication.

However, from 2019, due to a moralistic, religious and conservative hegemonic agenda in various sectors of the Republic, it becomes very unlikely the public investment in health promotion and prevention for PLHA. Even because, associated with the ultraconservative agenda, the ultraliberal economic plan, which had already been developing after the impeachment of the former president, and that got Congress to freeze public spending for 20 years, is in full expansion with the new Bolsonaro government.

This paper points to the need to intensify studies on the internet in relation to PLHA. Mediations that occur beyond consultation offices need to be better defined in order to expand care. How does this mediation work for people who are only connected through support groups, or only through social movements? And what is the situation for people with no group connections?

Questions relating to sexuality and the use of condoms, adherence to medications and the power of the internet to influence people need to be radicalized from the point of view of analysis, so that it becomes possible to broaden the structuralist view regarding epidemiological surveillance.

Reception studies, focal groups and, especially, monitoring and analysis of social media are other possible methods that go beyond virtual ethnography, in the sense of widening the analysis on people’s use of the internet and how they relate to other people, at a certain instant, in a post, after so many different comments and recommendations.

Lastly, the notion of online and offline needs to be deconstructed. The need for interaction with other people as a matter of survival of the human being is, despite its contradictions, one of the human conditions of higher intrinsic value. Humanity has always been online, and offline movements generally lead to misunderstanding, wars and isolation. Those who believe that being alone is to be with yourself are wrong.

Authors’ contribution

Alfredo de Oliveira Neto participated in the design and delineation of the work and the discussion of the results, writing of the manuscript and approved the final version of the manuscript. Kenneth Rochel de Camargo Júnior participated in the design and delineation of the work and the discussion of the results and approved the final version of the manuscript.

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O estudo identificou e analisou algumas interações na internet no cotidiano de pessoas vivendo com HIV/AIDS (PVHA) no Brasil. Como método, realizamos entrevistas com PVHA utilizando análise de conteúdo e uma etnografia virtual de um grupo fechado de PVHA no Facebook. Chegamos aos seguintes resultados: a sociabilidade produzida na internet ajuda a reduzir o sofrimento em relação ao preconceito; não há muitos espaços de acolhimento para PVHA na internet; PVHA vinculadas às redes sociais têm mais incentivo para não desistir da medicação; as negociações sobre medicação e sintomas ocorrem nas redes sociais. Conclui-se que há necessidade de ter espaços de acolhimento às PVHA na internet garantidas por políticas públicas; educação médica precisa abordar questões relacionadas à internet e saúde.

Palavras-chave: Comunicação e saúde. Internet e saúde. HIV/AIDS. Sociologia da Internet. Etnografia virtual.

El estudio identificó y analizó algunas interacciones en internet en el cotidiano de personas que viven con VIH/SIDA (PVHA) en Brasil. Como método, realizamos entrevistas con PVHA utilizando análisis de contenido y una etnografía virtual de un grupo cerrado de PVHA en Facebook. Llegamos a los resultados siguientes: la sociabilidad producida en internet ayuda a reducir el sufrimiento con relación al prejuicio; no hay muchos espacios de acogida para PVHA en internet; PVHA vinculadas a las redes sociales tienen mayor incentivo para no desistir de la medicación; las negociaciones sobre medicación y síntomas ocurren en las redes sociales. Se concluye que existe la necesidad de tener espacios de acogida a PVHA en internet aseguradas por políticas públicas; la educación médica precisa abordar cuestiones relacionadas a internet y a la salud.

Palabras clave: Comunicación y salud. Internet y salud. VIH/SIDA. Sociología de Internet. Etnografía virtual.

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