

The Meaning of HIV-Risk Prevention among Internet Users with Bipolar Disorder

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Original Article

SUMMARY

Introduction

The persons with bipolar affective disorder (BAD) constitute a vulnerable group to HIV infection; in spite of that, little research has been done on the preventive culture in this population.

Objective

To identify meanings and practices on HIV transmission risk prevention among persons having a bipolar disorder, active members of the "Foro Bipolarmexico" weblog.

Methodology

A quality ethnographic study was carried out on a Mexican weblog, directed by and for persons with BAD. The sampling of forums of expression published from 2007 to 2010 was forthcoming. An inductive thematic content analysis was conducted and the ATLAS.ti software was used for the processing of information.

Results

The meanings and the conditions implied in the construction of practices on HIV transmission risk prevention cover three levels: a) psychobiological, where it is identified that the symptomatology associated with the disorder and the use of medication are implicated in the alteration of sex drives and practices; in the presence of this, bloggers propose activities allowing channeling of sex drive, change of medication and use of condoms; b) microsocioal, in which certain conditions stood out such as poor communication with their psychiatrists and partners on the disorder and its effect on sexuality, thus they promote open discussion on the changes experienced; and c) macrosocioal, where the stigma of the disease is expressed in the isolation and the difficulty to relate with steady couples, conditions that could be counteracted, as suggested, with the social recognition of their potentials.

The emphasis on the recuperation of meanings socially built proved that it is urgent to consider preventive interventions aimed both at individual risk practices and at microsocioal and macrosocioal conditions that take part in the vulnerability to HIV infection.

Key words: Bipolar disorder, prevention & control, HIV, weblog, social support networks.

RESUMEN

Introducción

Las personas con trastorno afectivo bipolar (TAB) constituyen un grupo vulnerable al contagio del VIH; a pesar de ello, poco se ha investigado sobre la cultura preventiva en esta población.

Objetivo

Identificar los significados y prácticas sobre la prevención del riesgo de transmisión de VIH en personas con trastorno bipolar, miembros activos del weblog "Foro Bipolarmexico".

Metodología

Se realizó un estudio cualitativo de tipo etnográfico en una *weblog* mexicana, dirigida por y para personas con TAB. El muestreo de foros de expresión publicados de 2007 a 2010 fue propositivo. Se realizó un análisis de contenido temático inductivo y para el procesamiento de la información se utilizó el software ATLAS.ti.

Resultados

Los significados y las condiciones implicadas en la construcción de prácticas sobre la prevención del riesgo de transmisión de VIH abarcan tres niveles: a) el psicobiológico, donde se identifica que la sintomatología asociada al trastorno y el uso de medicamentos están implicados en la alteración de deseos y prácticas sexuales; ante esto los bloggers proponen realizar actividades que permitan la canalización del impulso sexual, el cambio de medicamentos y utilizar preservativos; b) el microsocioal, en el cual destacaron condiciones como la deficiente comunicación con sus psiquiatras y parejas sobre el trastorno y su efecto en la sexualidad, por lo que ellos promueven la discusión abierta sobre los cambios experimentados y c) el macrosocioal, donde el estigma de la enfermedad se expresa en el aislamiento y dificultad para relacionarse con parejas estables, condiciones que podrían contrarrestarse, según sugieren, con el reconocimiento social de sus potencialidades.

El énfasis en la recuperación de significados construidos socialmente evidenció que es apremiante considerar intervenciones preventivas dirigidas tanto a las prácticas de riesgo individuales como hacia las condiciones microsocioales y macrosocioales que participan en la vulnerabilidad al contagio de VIH.

Palabras clave: Trastorno bipolar, prevención, VIH, *weblog*, redes de apoyo social.

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INTRODUCTION

People with severe mental disorders (SMD), such as the bipolar affective disorder (BAD), constitute a high vulnerable group for the human immunodeficiency virus (HIV) infection risk. For this population Joska et al.¹ reported a high HIV seroprevalence (10%, range 0-59.3%), with an increasing time trend. By 1996, the seroprevalence ranged between 0 and 22.9%, while after 1996 ranged between 6 and 59.3%.

Reasons why persons with BAD are comparatively more vulnerable to this infection, as compared to persons suffering other disorders, are the following: 1. they have sexual intercourse more often than schizoaffective² and depressive patients;^{3,4} 2. in women there is a higher number of sexually transmitted diseases (STD) in the course of their than in unipolar depressive patients;⁵ 3. they have higher seropositivity;⁶ and 4. they have more risk factors.⁷

A study conducted in the United States involving population with BAD found that the higher use of psychoactive substances, the lower psychiatric severity and the presence of a recent manic episode were predictive factors significant for the HIV transmission risk.⁸ On the other hand, a study conducted in Nigerian adolescents with bipolarism found that comorbidity, mainly with disorders related to the use of psychoactive substances, was significantly associated with the sexual risk behavior, especially in men. Likewise, it was identified that the higher frequency of religious practices and having parents married under civil law result in a protective effect on unsafe sexual practices.⁹

Few qualitative studios have been made focused on understanding the sociocultural factors associated with unsafe sexual practices in psychiatric populations. Collins, Unge and Armbrister¹⁰ found that marginalized ethnicity, the transnational immigrant status, poverty and gender inequalities cause a greater vulnerability to HIV transmission risk in Hispanic and black women with SMD living in the United States. However, there are no reports related to the construction of meanings of unsafe sexual practices prevention in persons suffering from a bipolar disorder.

This paper proposes an approach to the vulnerability problem of these persons, from a culture point of view, that is to say, understanding the "subordinate" voices of those who live the situation, so that they may explain the risks and barriers that are prejudicial to the preventive actions.

We consider culture as a dynamic and complex network of meanings in constant flow, which interact with the structural processes surrounding such network; where meanings are built by the actors.¹¹ In this regard, there is a serious discussion based on whether Internet can be considered culture or a cultural device, which reconsiders the distinction between what is real and what is virtual, as well as its methodological implications. Therefore, it should be considered that the production of sense in the Internet interaction occurs with the understanding of the conditions in

which the Internet is used, as well as the writing context and the social spaces that emerge in its use.¹²

Then, a virtual community may be seen as a space where meanings emerge, but the meanings and the perceptions provided by their members shape up according to the environment where they come from. Studies conducted on the social impact of virtual communities show that this participation have influence on the change of opinions, preferences and actions of their members.¹³ Furthermore, this affects the decision making, since it implies a change in the perception about what occurs, and even in themselves.¹⁴ Considering the foregoing, we may assume that this social interaction may induce changes in sexual practices and the perception of HIV risk.

The purpose of this study is to identify meanings and practices on HIV transmission risk prevention among persons suffering from a bipolar disorder being active members of the "Foro Bipolarmexico" weblog.

MATERIALS AND METHODS

A qualitative study was made under the approach of the ethnographic method of weblogs.^{12,15} The assumptions of this method were applied to carry out a holistic approach to the virtual interaction environment and the cultural connectivity process of the "Foro Bipolarmexico" weblog, which includes a community of persons with BAD.

The sampling of forums of expression published from September 2007 -the starting date of the virtual community- to March 2010 was forthcoming.¹⁶ The "forum index" was reviewed and three forums were selected that allowed the generation of dialogues about feelings and experiences regarding sexual practices and the HIV/AIDS risk: "General Forum", "General Information" and "Ask Others".

Subsequently, the topics included in each forum were reviewed and the subtopics most read and/or answered by the members or visitors were chosen. This information was obtained from the same forum, since each entry is recorded thereof.

As for the organization of the material, conversations of the selected topics were copied in a word processor including a link that allowed one to connect with the complete information and its discursive context.

For the information analysis, processes of inductive thematic content analysis were used.¹⁷ The coding of the information implied reading the texts and their fragmentation in subject matters that were subsequently grouped in three major categories: psychobiological, microsocioal and macrosocioal aspects.

At the end, an interpretive synthesis was built based on the relations of topics from the three major categories, in order to generate a model about the risk and prevention culture expressed by the forum members.

To access the forum and describe it, the main author of the study registered in the weblog. First, she took part as a visitor without specifying her status. Then, as a relative of a person with BAD, and during the analysis process she introduced herself before the forum audience as a researcher requesting the manager –in writing– his consent to use the weblog information. The forum manager, as well as all members who answered the post, replied affirmatively to the request.

RESULTS

The methodological procedure allowed identifying that the topic of sexuality is a field of interest for persons with BAD, especially due to the difficulties they face for living with this disorder. Out of 592 subtopics included in the first general topic (“Introduce Yourself and Tell Us About Your Case”), “Increase of Sex Drive” ranked 22nd, with 177 readings and 12 answers, as of March 8, 2010.

This methodological procedure allows perceiving fields of opportunity for the research of this disorder, representing the most urgent needs for the members of this blog. Among such needs are: a) the social stigma of the illness; b) the difficulty to control the illness due to inefficient treatments, misdiagnoses and a conflictive relationship with the mental health care providers; and c) the lack of accurate the disorder information to society.

Below is a description of the characteristics of the virtual community and the main findings on the meanings of prevention and risk, for the purposes of the conditions generated by the disorder.

Characteristics of the Analyzed Weblog

The “Foro Bipolarméxico” weblog (<http://bipolarmexico.foros.ws>) was published on the Internet in September 2007. Since then, it compiles in chronological order texts written by the members of the virtual community –most of them Mexicans-, who voluntarily share their experiences.

The creator of the site, whose alias is “Leónidas”, suffers from BAD, and built the community with a humanist approach of mutual support. This approach is reflected on the stories where several members express the invaluable support given by this weblog for them and their families.

The blog’s service is offered by “foros.ws”, a website that allows one to create a forum –free of charge; which purpose is to provide a tool to create communities. The website of the forum contents the following sections: a) Home, a welcome section where new materials are outlined; b) Forum Index; c) My Favorites, where topics of greatest interest are added; and d) Ranks, including lists of the most active members and of the persons registered in the blog (710 as of 8 March, 2010), as well as the services of private messaging and user groups.

The blog is a space where persons suffering this disorder and their families make up a virtual community based on the expression of comments, spreading of photographs and videos, and development of dialogues and debates on different topics.

Participation of forum members is anonymous, which allows several possibilities of expression and social support mechanisms in the interaction. However, the manner of participation also implies the possibility of “fake” members (users pretending to be other users or who do not have the disorder or are not relatives of a person with BAD). Thus, it is important to consider that the forum could have some contents that were not necessarily replied by the population of interest.

Expression of Meanings on Prevention

The thematic content analysis allowed identifying three expression levels of elements related to the construction of meanings of HIV-transmission risk prevention in participating members of the “Foro Bipolarméxico”: 1. the psychobiological elements level, 2. the microsocial level and 3. the macrosocial level. Each level is described below.

Psychobiological Elements

This level includes characteristics inherent in the illness (manic, hypomanic and depressive episodes and the use of medication) identified as related to risk practices and meanings of HIV prevention. Table 1 displays some examples about the conversations of bloggers referred to each category.

Between Impulsive Mania and Subsoil Libido. Both men and women state in the forum that the BAD itself –and because of the use of medication to control it– has effects in sexual satisfaction and in self-care.

On the one hand, they say that under the mania status an increase of sex drive and the loss of impulse control are experienced, which in some cases implies unsafe sexual practices (see subcategory: impulsive mania).

The increase of sex drive is considered a problem –mainly among women–, which can be controlled with the use of medication, but having as a side effect the reduction of sex drive. The medication referred by the bloggers is an antidepressant made up by paroxetine hydrochloride, a selective inhibitor of serotonin capture.

On the other hand, they also notice that the use of this medication reduces its libido to such a degree that it may cause an important problem for those who have conjugal life. As some women notice, decrease in sexual activity may drive their partners to have sexual practices with other people.

An element that comes up from the conversations is the different opinion between men and women regarding their partners’ “infidelity”. For women it is a circumstance that can be put up with when they decrease their sexual

Table 1. Psychobiological Elements

Category. Between Impulsive Mania and Subsoil Libido	
Subcategories	Conversations of Participants
Impulsive mania	<p>“Woman (W): [...] as I mentioned before, I’ve recently felt like having ‘physical contact’ with persons I like. I think that it’s normal to have such a desire for a person, but in two weeks I’ve been with 3 different persons and my desire has grown more and more.</p> <p>Man (M): You don’t have to feel different or strange. I believe this happens to most of us (bipolars)...ⁱⁱ We lose control in sex matters, either downward or upward... Depending on our mood... In general, the uncontrollable sex drive is associated with mania.</p> <p>W: [...] It is quite possible to be unfaithfulⁱⁱⁱ when one is under a state of mania, because of the euphoric state and the high libido. But some of us behave ourselves well; it’s difficult for me though, hahaha.^{iv} We can’t use our illnesses as an excuse for our acts [...].”</p>
Subsoil libido:	<p>“W: You should tell your psychiatrist to prescribe you [an antidepressant composed by paroxetine],^v which as a side effect lowers libido to the subsoil. I mean it—I take it and practically I don’t feel like doing it. Thus, you neither run the risk of getting pregnant nor getting infected.</p>
Reduction of libido and medications	<p>W: [...] I also take it [same medication referred by the other woman]. You’re totally right! It’s unbelievable that a medication can do that in my mind and body. I’m telling you this because I just recently have a partner, and it’s practically IMPOSSIBLE to be sexually satisfied. The good news is that my doctor will suspend it during the next few weeks (now I’m taking the minimum dose) and I’ll be the same woman again! [...]. I hope I can control that, although I practically have understood that those hypersexuality outbursts are more common when I’m under a total state of mania.</p> <p>W: That’s not a problem when one lives alone, but I have a husband and he has to pick up the tab.^{vi} I tried to stop taking [an antidepressant composed by paroxetine] and the doctor changed it, but it made me crazy! [...] This time I’ll try to make an effort to maintain normality in my marriage, considering the few things that it [an antidepressant composed by paroxetine] lets me do.”</p>
Reduction of libido and depression	<p>“W: Depression is the first factor of sexual dysfunction +^{vii} [an antidepressant composed by paroxetine] leaves me totally unfit.</p> <p>W: When I’m manic he’s happy because our relations are renewed, but when I’m depressed we don’t have sexual relations for some weeks. It’s incredible how he’s adapted.</p> <p>M: [...] Regarding sex, as our fellow says, it’s almost nil in moments of depression, but I think it shouldn’t be a problem if there is real love.</p> <p>W: [...] Now I’m going through a bad patch in my marriage... My libido is low.... I know that this would not justify my husband’s behavior... But I’d understand him and probably I’d forgive him.</p> <p>M: From my way to understand love: no, I wouldn’t forgive him. Not only that, if it was the other way round —if I was the unfaithful one— he’d break up the relation, since living with that forever is like an eternal scar, giving rise to doubts, unease, guilt and of course something, a part of that love, would have died forever... trust.”</p>
Category. Risk Prevention: Between Fleeting Stability and Emotional Lack of Control	
Subcategories	Conversations of Participants
Prevention strategies	<p>“W: I’ve talked with my psychiatrist about this and we’re actually working on it right now. It’s important because it can be risky for me. You know how impulsivity is... No protection, pregnancy, etc.</p> <p>W: As Pulpo says, you can try to lower it with occupational therapy; it’s a good idea! My recommendation is that if you can’t control yourself do what you feel like but taking precautions. Remember, not only there’s a risk of getting pregnant but also to be infected by an illness like HIV.</p> <p>M: [...] Solve it??^{viii} That’s really difficult... 😬 it’s a very strong impulse that even seems to be uncontrollable. Thus, the only solution (for me) is channeling to any other area, either art, computers or even cleaning my house, hahaha... If the impulse is already much stronger than I satisfy it, but with a lot of caution; since, as you say, you run the risk —in the whirlpool of desire^{ix} - to even have contact with unknown persons, with unknown intentions.”</p>
Fleeting stability and emotional lack of control	<p>“M: Stability is a place where we (bipolars) only visit for a little while.</p> <p>W: Isn’t it true?... I live in a permanent relapse. I’m in euthymia briefly and then: smack!, I go down again [...] And it’s not for a lack of precaution, since I take care more and more precautions but it doesn’t work.</p> <p>M: Since I was 21 years old all psychiatrists prescribed me all kinds of “antidepressants”. Two years ago I realized that these “antidepressants” do not work for my case. I’ve taken MAOIs, TCAs, SSRIs, duals, mianserins, many types of neuroleptics, “typical and atypical [...] but the thing is that, after all, a psychiatrist I visited 2 years ago (at the age of 38) diagnosed me with bipolar disorder, [...] hopefully, this time —after 20 years of taking psychotropic drugs— I can see a light of victory.</p> <p>W: [...] with [a second-generation antipsychotic drug composed by benzisoxazole and piperidine] I fattened up a lot; I became a cow!... And to top it all, it lowered any sex drive... Hahaha.... There’s no way I’ll take it again....</p> <p>W: At the end I told my doctor that I didn’t want to keep taking the valproic acid. I asked him to prescribe me another medication. I used to make myself vomit to avoid gaining weight. That’s why I told him to try another one. With the medicine change I lost the excess weight and my joy came back. Being fat is depressive.”</p>

activity, but this does not apply to men (see subcategory: subsoil libido).

Risk Prevention: Between Fleeting Stability and Emotional Lack of Control. The forum participants –both female and male– that perceive the risk of HIV transmission and unintended pregnancies when experiencing the increase of sex drive expressed possible strategies to avoid risky practices. In their conversations they mention the seeking help in the psychiatric therapy, the channeling of sex drive with occupational therapies and the use of contraceptives and protection against diseases when sex drive is “uncontrollable” (see subcategory: prevention strategies).

Nevertheless, for some forum members the opportunities of prevention strategies use are diminished by the emotional instability characterizing the BAD. Such instability is originated due to the lack of control of the BAD, the poor efficiency of the different treatments and the patients’ rejection to use medication because of their side effects. As for the poor efficiency of treatments, a forum member expressed that, in his case, the prescription was incorrect due to the wrong diagnosis of his disorder, which lasted for years.

Regarding side effects of drug treatments, the reduction of sex drive and weight gain caused a major rejection towards medication among the forum participants (see subcategory: fleeting stability and emotional lack of control).

Therefore the prevention strategies they suggest should be considered for the purposes of BAD’s control.

Microsocial Level of Risk

This level involves social interactions related to the disorder perception and its impact on couple relationships. Table 2 shows some examples of bloggers conversations referred to the category.

Negative Social Perception Effect. The control of BAD and its effects on sexual practices not only relates to medical issues but also to the negative perception of the disorder.

There are social conditions related to such practices, among them is the social isolation that affects the formation of steady couples fearing rejection. A woman of the forum emphasizes her isolation situation, and a man talks about the option to use commercial sex because of the difficulty to establish firm sentimental relations (see subcategory: social isolation).

When persons with a bipolar disorder are sexually active and their couples perceive the illness as madness, the latter do not take the relationship seriously and tend to abandon them. The above is described by a forum participant who shares that a friend introduced him his bipolar couple (see subcategory: madness and discrimination).

On the other hand, dynamics of marital relations based on a negative perception of the illness generates sentimental conflicts expressed in rejection and guilt. In the case of women, sometimes the feeling of guilt and their self-perception as unworthy of their couples’ love and support justify

Table 2. Microsocial Level of Risk

Category. Negative Social Perception Effect	
Subcategories	Conversations of Participants
Social isolation	<p>“W: [...] What affects me is the lack of friends. Sometimes I wonder: what’s going on? What’s my problem? Am I a concealed person or what?? Hahaha[...]. I hardly go out and haven’t had a boyfriend for years. I haven’t kissed anybody in five years, hehehe.</p> <p>M: I’ve never had a girlfriend. I loved a girl madly but I was ashamed to tell her I’m bipolar, so I stopped seeing her. It’s a big mistake I’ll be regretting all my life because she got married... I’ve never had a loving kiss. I had been kissed, but when I’ve paid for sex. My situation is really painful when it comes to sentimental relations. I’m not ashamed to say this, since it’s the truth.”</p>
Madness and discrimination	<p>“M: [...] a guy^{xi} who doesn’t know about my illness told me that he met a girl who was not attractive but dressed up a lot and liked parties badly. He even told me he could introduce me to her because they’ve been dating a whole month and they’ve had sex like 10 times. The thing is that –as she thought this guy wanted a more formal relation– she told him she was bipolar. As a result of that he stopped seeing her little by little. With us, he even referred to her as “la Lore” (Lorenza).^{xii} He’d sex with her until he got tired and goodbye! When the girl called him (as is normal whether being ill or not) asking for explanations, he was feeling hounded and suffocated. He even thought that she’d follow him and those kind of thins. I asked him why he was thinking that, and he answered that she was crazy, that he’d already watched on TV what bipolars could do!!!”</p>
Steady couples and gender	<p>“W: [...] I’ve been married for 4 years. My husband is a very good person [...] When we got married I didn’t tell him about my illness because I couldn’t believe it [...] The problem is that I don’t get better and he’s started to change; he goes out alone. I told him we should separate, since I don’t want to keep ruining his life. I know that living with a person like me is very difficult, but he doesn’t want to leave me and I don’t get better at all. I don’t know what to do.</p> <p>W: [...], My family and couple life has been pretty deteriorated. Of course, my husband supports me a lot; but gets tired and annoyed. I understand him and thank him everything-everything-everything. He often reminds me how tough is to live with me. How long will he resist? How long his patience and love will last? He’s trying to love the “new being” I’ve become, but it terrifies me the fact that it’s a kind of trial, with inquisitive eyes before my acts.</p> <p>M: I love my wife a lot, however, I’ve hurt her (only morally, never physically) [...] When I’m conscious I realize that I’ve hurt her... Of course, this problem is weakening love... [...] we live the illness as well as those who are beside us...”</p>

Table 3. Macrosocial Level of Risk

Category. Social Stigmatization: Demonization is in Fashion	
Subcategories	Conversations of Participants
Stigma and guilt	<p>"M: Two years ago my world turned upside down. At work, I started to distort reality to such an extent that I thought there was a conspiracy against me... Hehe, [...] Well, I had a couple of friends in that time. We were "inseparable" friends [...]. They witnessed how I evolved to that state and —to the same extent— they increasingly started to get away from me. [...] After a year I was depressed. My psychiatrist recommended me to contact them in order to resolve pending issues, combat my isolation; at that time I needed motivation. I did so.[...] Nevertheless, they didn't call me, [...] I thought: It's OK, I understand that they want to get away when I'm having a paranoid pattern, but not when there's no mania [...] My psychologist puts hardly insists that I should think what they felt when I had my "madness" [...] She tells me to acknowledge that I'm too far away from being well, [...] that this contributes to rejection. I think we're making a lot of excuses to justify their actions [...] She also encourages me to realize that sanity is a highly appreciated value in social life; therefore, the lack of sanity is highly stigmatized. [...] But what is all about? To approve everything that is not understandable, even actions that originate on stigmatization?"</p>
Bipolar fashion and demonization	<p>"M: Sure! There's an enormous stigmatization. I agree that a large part of the lack of information comes from TV, as the root of so many other evils.</p> <p>W: Recently, I'm very upset because I hear the word bipolar everywhere; but I'm especially annoyed because of the meaning people give to such word 😞. It now turns out that anyone who gets angry, screams or simply has a bad temper is a bipolar person! I've watched on TV a great number of documentaries, and I think that is OK that people know more about bipolarism but aren't we somehow demonized.....?</p> <p>W: [...] We're really capable and worthy of living a beautiful, calm and happy life, with no horrible stigmas devaluating our integrity.</p> <p>M: [...] TV series like CSI, Brother's and Sister's, Twenty-Four Hours, and now in Mexico, Mujeres Asesinas, are crime fiction programs that regularly end: "Mr. So-and-so was diagnosed as a bipolar person with schizophrenia". That is: "attention" the term is quite explicit, whether we like it or not, those who watch these TV series (millions of people) associate bipolar = murderer. Now, do you understand how serious this is? [...] Yesterday night I went out to dinner with a girl. In our after-dinner conversation I asked her about her hobbies; among other things she talked about TV series, and she named some of the above series. Then, she told me about a specific chapter and —of course— the bipolars thing came up. In her mind she knows very well that a bipolar person only causes problems (haha; it's the truth, but not always). I'm telling this because she'd never date a bipolar person because they are lunatics and murderers, and why does she think this? Obviously, thanks to TV!!! Try to meditate on this point! But don't worry, bros! Now, I'll have sex with her until I've got tired so that I can avenge the girl that my friend mistreated! Hahahaha, I'm kidding. I'm certain that I won't see her again for being so silly!!"</p>
Accurate information of bipolarism	<p>"M: [...] The illness can be defeated. But something makes me angry: the openness of the media—where we're portrayed as weirdos"</p> <p>"W: Besides the existing stigmatization, we sabotage ourselves because we don't investigate our illness and because we don't tell people its characteristics. Ignorance is combated with information; and we're responsible to bring this information to more and more people..."</p>

Categoría: El potencial de la genialidad y la sensibilidad

Conversations of Participants

"W: I see every bipolar person as a genius. We see life from another perspective and a huge sensitivity.

M: [...] We can achieve wonderful things; we've got that capacity. Bipolar and health people, no discrimination.

W: Through all these people it's evident that the bipolar disorder can be managed. People who suffered from a bipolar disorder have a great deal to offer to this world".

M: [...] We could compare the bipolar disorder with something. I compared it with a chainsaw. When I was told I was suffering from this condition, I took the chainsaw and —as I didn't how to use it— I destroyed many things around me. I hurt myself a lot with no real purpose, since I refused to accept it as something potentially constructive. This disorder is like a chainsaw; if you investigate its purpose and its correct use you can make wonderful sculptures with the hardest materials, although it might be difficult to master it..."

ⁱ While we tried to integrate the text of the conversations, as it appears on the blog, some paragraphs were edited, eliminating parts that were not very relevant for bloggers' discussion. Such editing can be detected where square brackets [...] appear. Also, the texts were slightly modified in order to obtain a better understanding, only adding accents in some words and punctuation in some sentences.

ⁱⁱ Ellipses that are not between square brackets are part of the text written by bloggers themselves; they do not refer to the edition mentioned in the previous footnote.

ⁱⁱⁱ Bloggers tend to modify words using letters that do not correspond to the officially admitted word. For example, the expression "ke" ["wat"] instead of "que" ["what"], or they write incomplete words like "porq" ["becs"] to say "porque" ["because"] and "q" ["t"] for "que" ["that"]. Nevertheless, these terms are understood among users.

^{iv} They also use expressions such as "hahaha" to indicate their mood, in this case: laugh or happiness, or they use images like: 😞

^v Paroxetine is an antidepressant, a selective inhibitor of serotonin capture. Mainly used to treat different kinds of depression, including reactive and serious depression, and depression accompanied by anxiety.

^{vi} The expression "he has to pick up the tab" ("él paga los platos rotos") in this context is used for referring to someone who is affected by a situation caused by another person.

^{vii} They use signs such as "+", in order to express "more" or "x" to express "for" or "=" for "equal/the same"

^{viii} The repetition of symbols like "???" is used to emphasize an expression, in this case a question.

^{ix} Some bloggers use metaphors to explain their emotions, experiences and expectations such as "whirlpool of desire" ("remolino del deseo") or "I can see a light of victory" ("la luz que me esté esperando para la victoria"), as well as analogies to represent in an amusing way their thoughts about their social appearance: "I became a cow" ("estar como vaca"), "weirdos" ("bichos raros").

^x It is important to emphasize that bloggers use specialized terms in the area of psychology and psychiatry such as "hypersexuality, impulse control, libido, euthymia" among others, as well as many names of medications they have used.

^{xi} Expressions like "brother", "bros" or "guy" are used to refer to a person with whom they have a friendship bond.

^{xii} Expressions such as "La Lore" "Lorenza" is a pejorative way they related to the condition of the mental illness; in the context this can be understood as silly, insane, among others.

the psychological violence they have to face. However, men suffer from couple confrontation that comes up when the disorder occurs with aggressions, which weakens the couple relationship (see subcategory: steady couples and gender).

Macrosocial Level of Risk

In this is included the dimension of the illness social stigma and its impact on couple relationships. Table 3 displays some examples about the conversations of bloggers referred to each category.

Social Stigmatization: Demonization is in Fashion. Social rejection of persons with bipolar disorder is based on the lack of understanding and the social perception that consider them as lunatics and insane persons. This stigmatization grows when the responsibility falls on the person who has the disorder, instead of fostering a culture of information where these persons can be understood (see subcategory: stigma and guilt).

Some blog members criticize the stigma situation, generated by the false information on bipolar disorder that has disseminated through the mass media. High frequency of notes and documentaries on the topic has made this issue “fashionable”, often without clarifying what this diagnosis involves, which is indistinctly applied to those who behave “strangely”. Thus, the treatment of information has caused the demonization of persons with BAD.

Two women of the forum say that this “fashion” has caused rejection, discrimination and devaluation of their integrity by peers. Likewise, this “marks” their interpersonal relations, having influence on their sexual practices. As the BAD is massively stigmatized, persons who are around of sufferers reject the possibility to establish a steady relationship feeling discriminated, “demonized”, then they tend to establish occasional couple relationships or suffer abuse from their partners, especially in the case of women (see subcategory: bipolar fashion and demonization).

The forum has put forward the necessity that the media refers positively to the disorder, spreading the information correctly. One of the topics proposed for discussion among members entitles: “*We’re not Pretty but We’re in Fashion*”. As mentioned above, the most difficult thing to face in their disorder is the social stigma (see subcategory: accurate information of bipolarism).

The Potential of Peculiarity and Sensitivity. As previously described, the perceived stigma causes social isolation in persons with this disorder, which is related to risky practices such as having sexual relations with unknown persons or with commercial sex workers. Also, the self-devaluation experienced because of social rejection can involve alienation from loved ones and abuse by their sexual partners.

Besides putting forward the fact of facing social stigma through the correct information of the disorder as a strategy to avoid social isolation and abuse, the blog participants

insist on the acknowledgment of their potentials, by using –as a reference– celebrities who suffer from the disorder. Among these potentials the fact of having a different perspective about life and a special sensitivity stands out.

A participant of the forum mentions the chainsaw’s metaphor; he compares this tool with bipolarism proving that the ignorance of its use and its characteristics is risky because of the harm that can be caused to oneself and to others. However, when one knows well the tool, it is possible to control and use it positively taking advantage of its potential (see: Potential of Peculiarity and Sensitivity).

DISCUSSION

This study produced an ethnography of the virtual community called “*Foro Bipolarméxico*”, a social interaction space with identification and attachment among its members, which provides accompaniment in processes of anguish and information based on experience.

The meanings of prevention in persons suffering a bipolar disorder seem to be conditioned by several psychobiological, microsocio and macrosocio factors that are in turn connected and involved in sexual practices of this population.

The conversation about topics of interest and on their experiences offered a valuable resource for the development of this research concerned with the understanding of meanings socially built on HIV prevention. The subtitles: *Between Impulsive Mania and Subsoil Libido; Risk Prevention: Between Fleeting Stability and Emotional Lack of Control; Negative Social Perception Effect; Social Stigmatization: Demonization is in Fashion; and The Potential of Peculiarity and Sensitivity* illustrate some meanings built by the participants, which also show the conditions that may be involved in the vulnerability towards the HIV risk.

The episodes inherent in the illness and the medication; the little discussion on sexual topics among patients, their partners and health care providers; and the stigma of the illness were the three pillars where it is possible to notice the conditions that damage this population and the prevention strategies that have been suggested to neutralize it.

Disturbances on sex drive and sexual activity during the manic, hypomanic and depressive episodes coincide with clinical literature.¹⁸ Furthermore, the impulsivity and the increase of sex drive and sexual activity experienced by the bloggers in mania have also been recorded in studies conducted in different countries, which prove that hypersexuality and impulse control reduction occur in 40-60% of population during these episodes.¹⁹ On the other hand, other studies show connections between risk practices in the recent manic episode and the comorbidity of psychoactive substances use.^{8,9}

In the case of the depressive episode, we identified that its symptomatology and the use of medication reduce

sex drive and sexual activity, an evidence that is similar to clinical studies where the depressive episode and some pharmacological treatments such as antidepressant, atypical antipsychotics, as well as mood stabilizers (as lithium and antiepileptic drugs), are related to the person's sexual activity or satisfaction.²⁰ It could be deduced that this sex drive and sexual activity reduction in depressive episodes implies a risky behavior reduction for HIV transmission, nevertheless, it does not always occur. In adolescents with depression certain connections between symptomatology and risky sexual practices for HIV transmission have been identified.²¹

In this study we found that in the reduction of sexual activity there is no risk perception at all; however, some women think that this situation causes their couples to seek occasional relationships. This relationship dynamics, in which the woman knows and – at a certain extent – accepts the sexual practices of her partner, is little visualized as a dynamics that damage her in the face of the virus transmission risk.

The effect of the sex drive and sexual activity reduction that the participants have experienced with some medications suggests that some of them could be used to counteract hypersexuality in the mania. However, self-administration of antidepressant medications which compound is paroxetine could worsen their suffering, considering that the unsupervised use of these medications in the absence of a mood stabilizer may cause a turn to mania.²²

This research reflects an important concern of blog members regarding the increase of their sex drive and their sexual practices during manic episodes, the sexual activity reduction during depression and the use of medication. Additionally, it emphasizes a lack of information – especially in those that have a short time with this suffering – on the disorder and on the effect of medication.

As preventative measures in this level, which may be designated as a psychobiological level, participants suggest that either the uncontrollable sex drive they sometimes experience should be channeled to recreational activities, or a change of medication should be requested or, if this does not work, they should use condoms.

This would mean that some persons with bipolar disorder could have a symptomatology related to unsafe sexual practices that should need individual care. Nevertheless, the symptomatology does not determine the risk; there are other psychosocial and structural factors involved in the vulnerability, which in turn are to be considered as pillars in prevention: a) inform about the symptomatology and its effect on sex drive and sexual function to the person who suffers this illness and to his/her relatives in order to detect sexuality-related disturbances in a timely fashion, and to generate sexual health psychoeducational and/or pharmacological strategies; b) to foster open discussion of sexuality, preventive measures and HIV risk with their couple

relationships; and c) to identify whether a stigmatized risk perception exists in their lives, as well as the way in which such perception has socially been built as persons with a mental disorder.

The ignorance of the effect that the bipolar disorder and medications have on sexual practices causes anguish and lack of understanding in those who live this suffering and in their partners. An study conducted on partners of persons with BAD found that conflicts are mainly generated during manic episodes and when there is ignorance of such disturbances.²³

The effects of sexuality ignorance are such that not only cause spousal conflicts and a HIV transmission risk. A paper on persons with BAD found that the disturbances in their sexual life were significantly associated with attempted suicide.⁴

The virtual community participants sought answers in the forum due to their necessities and the lack of information that should be provided by mental health care professionals. Empirical evidence exists that they seldom or never discuss aspects such as the possible sexuality disturbances and HIV/AIDS prevention with patients suffering from TMS.²⁴ Most of the participants in this kind of researches state that they obtained further information from others sources.^{25,26} Despite many studies state that it is necessary that psychiatrists and other mental health care professionals provide information and training on STDs, HIV/AIDS and risky sexual practices, little has been done about this.^{23,27-29}

In this regard, a negative perception of the illness or the ignorance of the symptomatology in the sexual sense may cause relationship conflicts and abandonment. Bloggers themselves are proposing that these topics should be discussed with their psychiatrists and with their partners in order to achieve a better understanding and care for the body.

Largely, lack of information is due to the stigma of the mental illness; persons with a bipolar disorder – like most of persons with severe mental disorders – are invisible as a vulnerable group with health care needs, with capabilities of production and social development; and are only visible for discrimination purposes.

Stigma is a structural element in the understanding of the meanings of prevention and their sexual practices. Virtual community members explain and criticize the stigmatization they experience, expressed in the rejection, discrimination and devaluation of their integrity as human beings. Some studies have tackled stigma in persons with BAD finding that their interpersonal relations are undermined, as well as the possibility to control the symptomatology, which generates further deterioration.^{30,31}

Bloggers discuss extensively this social barrier, both as a condition that promotes ignorance and a phenomenon that affects the type of social and couple relationships they start. For some of them, having sexual relations with occasional

partners or with commercial sex workers is part of everyday life due to the lack of stability that they have in their couple relationships, which makes them feel sick, looked down and devaluated because of their symptoms.

These results coincide with two studies conducted in the United States and Brazil, since they show the influence stigma has on the type of relationships of persons with TMS, with the impossibility of the direct discussion of their sexuality and the limited prevention of STDs.^{32,33} In this case, bloggers promote that their capabilities are socially recognized and that they are properly notified about the disorder.

Some resources identified for the risk prevention at a microsocial and macrosocial level are: open discussion on the effect of the disorder and of medications on sexual practices both with patients and with relatives; promote the appropriate information about the disorder through the mass media; and foster the attachment to social support networks such as this virtual community.

Finally, the gender dimension emerges among the data as a line to be developed due to the differential implications that appear in discussions between men and women. Women with this disorder are more vulnerable to the risk of abuse and sexual coercion than men. On the one hand, men are the most vulnerable to the risk of social isolation associated to the stigma, which is expressed on a less frequent basis of steady couple relationships and relations with multiple occasional partners and, in turn, on less discussions on the sexual activity of their couples. This evidence is related to studies conducted in Anglo-Saxon countries with population suffering from TMS, which point out a significant major risk in men of a HIV infection due to the multiplicity of sexual partners,⁷ although they also show more prevention strategies, such as a more frequent use of condoms than women.³⁴ Also, women with severe mental disorders show high prevalences of sexual abuse.^{35,36} However, a more specialized work is required, which may contribute with the analysis of the discourses generated by men and women in order to gain a deeper understanding of the sociocultural conditions immersed in the experience of the suffering and in their sexual practices, including a gender perspective.

LIMITATIONS OF THE STUDY

The evidence hereby generated should be considered as part of a population making up this virtual community, which has access to the Internet, to the material resources and to the essential educational resources to chat in this blog. Also, it is a population with affordable access to formal mental health services; for example: psychiatry and psychotherapy. It is necessary to approach the population that lacks these resources, which is under a marginal situation and that possibly have different risk conditions and even greater vulnerability. It should be noted that poverty is a predictor for the

largest number of unsafe sexual practices,³⁵ according to studies conducted on American adults and on Puerto Rican women with TMS who lived in the United States. Poverty has been researched little and, much less, been compared with persons suffering from severe mental disorders from different socioeconomic strata.

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