

- ・ 浜松の財団の紹介で 5 人
- ・ snowball-sampling 法で 11 人

分析方法

- ・ 対象者一人に 6 回各 60 分面接を行った。
- ・ 3 人は東京都、2 人は埼玉県、15 人は静岡県で面接した。
- ・ 対象者から同意を得てインタビューを録音
- ・ その録音を起こして、エスノグラフ (Ethnograph コンピュータプログラム) によって内容データとして整理し、整理されたデータにコードを付け、システムック・ネットワーク理論 (Systemic networks)、フェミニスト理論 (Holland et.al.1998) と社会平等批判の枠組み (critical social justice framework) (Crock 2001) に基づいて分析した。

結果

- ・ 不安
- ・ 身体が自分のものではないように感じ (disembodiment)、
- ・ 性的関係を避ける (asexuality) という経験をもっていた。
- ・ 性的関係を取り戻すことができたものは、人生に対して楽観的な見方ができるようになっている。
- ・ エイズ治療薬は性欲に影響を及ぼすため、薬物 (ラッシュなど) やバイアグラを使用する傾向も見られる。
- ・ 自分の身体を取り戻すために、身体売買をする者もいる。
- ・ 性的志向に拘わらず、挿入セックスと陰茎中心主義 (phallocentrism) 的傾向が見られた。
- ・ HIV/AIDS におけるセクシュアリティの問題は、主として HIV 陰性の感染予防という観点から語られている。
- ・ セクシュアリティが人間にとって基本的な問題である以上、陽性者のセクシュアリティに注目する必要がある。
- ・ 本稿ではこうした観点から、陽性者のセクシュアリティを、さらには性的ニーズや抑圧一般を検討してみたい。

'Live a life or live a death': Embodiment and Sexual Experiences of some Latin American PLWHA men in Japan.

**Genaro Castro-Vazquez and Masayoshi Tarui,
Keio University Faculty of Letters**

Abstract

In this paper, we present the third part of our ethnographic investigation including HIV-positive Latin Americans living in Japan. In order to investigate the relationship between psychological wellbeing and sexual activity among informants, we interviewed 20 male HIV-positive Latin Americans living in Japan. From April to September, 2002 and August, 2004, we conducted a set of six sixty-minute-interviews with 20, 28-37-year-old HIV-positive males. Three of them were illegal aliens and seven of them claimed to be homosexual. Participants were contacted through a hospital, a NGO, and by snowball-sampling. Our analysis of the interviews indicates that concurrent with a negative attitude towards life informants feel disembodied and asexual after sero-conversion. However, after resuming their sex life they experience a positive attitudinal change and emotional release. Drug side-effects on libido make them use stimulants and Viagra. Phallocentrism, fears of infection and discrimination are obstacles to a full sex life. Informants look for casual sex and engage in prostitution in big cities. These findings have several implications for sex education practice.

Keywords

People Living with HIV/AIDS, Sexuality, Embodiment, Latin Americans, Japan

Introduction

We interviewed a group of 20 men in order to investigate the circumstances of Latin American people living with HIV/AIDS (PLWHA) in Japan. The first part of our investigation encompasses issues concerning the ways our informants receive medical treatment and information about their condition. We highlight the relevance of informed consent in providing medical care to immigrants living with HIV despite their sexual preference, ethnic and cultural background. Our findings suggest that our informants receive information concerning medical treatment, but informed consent does not take place in most cases. They are not advised either about alternative treatments or about the feasibility of seeking a second opinion. We recognise that informed consent and communication in general between foreign PLWHA and the Japanese health care providers appears to be largely obstructed. Communication is not attained because fears concerning non-consensual disclosure and the self-perception migrants have of their alienation living in a foreign county. In addition, communication is blocked by breaches of trust due to having experienced homophobia and fear of deportation as some of our informants are illegal aliens. Finally, our informants expressed that communicating with physician is difficult because of paternalistic

attitudes and unavailability of proper medical services directed to foreign people. Although issues concerning informed consent are our main objective, the results of our investigation indicate that the lack of psychological support troubles most of our informants. We find that rather than mere informed consent most of our informants desperately need the assistance of mental health professionals, as they are more prone to experience a decrease in their CD4¹ and an increase in their viral load² because of despair and anxiety. Psychological distress aggravates their illness. In the second part of our investigation we deal with issues concerning community support and HIV. We aim to shed light on the ways our informants relate to other Latin Americans. One of the factors related to the anxiety, depression and loneliness that our informants confront is largely connected to an almost complete lack of support from the people surrounding them. A second factor associated with their psychological distress is derived from their sexual life. Thus, the third part of our research deals with the embodiment and sexual experiences of our informants. Hence, we believe that an investigation of the sexual life of HIV positive people will result in sound strategies to that to enhance the quality of life of PLWHA and to improve HIV/AIDS and sexuality education in general.

The main issue our informants confront is the medicalisation of their lives. They can barely avoid the normative coercion implicit in the antiviral paradigm. None the less, we recognise that their sexual experiences are a valuable area of research to grasp the means by which they contest biomedical discourses and even attain re-embodiment.

Sexuality for PLWHA

The 2002 and 2004 global reports on HIV/AIDS state that comprehensive care for PLWHA needs to include sexual and reproductive services (UNAIDS 2002: 142; UNAIDS 2004: 112). However both documents basically emphasise matters concerning medical care availability and do not provide examples of programmes responding to the sexual needs of PLWHA. The pervasive influence of medicalisation and the perception of PLWHA as disable people in tandem with the lack of a cure or vaccine have rendered issues concerning PLWHAs' sexuality and reproductive health largely irrelevant. Although, in the literature, we did not find any recent study focusing on sex related issues of migrant PLWHA, we did find some investigations that shed light on how sero-conversion altered the sexual life of HIV carriers, and on how they cope with the threat of "living with death" (Heaphy 2000).

Weitz (1991) found in the literature a strong tendency to accept that physical decline leads to asexuality among HIV positive gays. In addition, based on their study with HIV positive gay men, Siegel and Ravies (1993) suggested that gay people adopt celibacy as a

¹ The CD4 is a molecule on the surface of some cells onto which HIV can bind. The CD4 cell count roughly reflects the state of the immune system. The CD4 count of a 'healthy' individual is 500 on average.

² Measurement of the amount of virus in a sample. HIV viral load indicates the extent to which HIV is reproducing in the body.

preventive measure due to their yearn for truly safe sex and a relationship rather than mere sex, uneasiness due to possible transmission, dislike of safer sex and the fear of being unable to control their sexual urges. However, Meyer-Bahlburg *et al.* (1991), and Gochros (1992) in line with Gold *et al.* (1994) found that after sero-conversion, gay men tend to experience periods of abstinence before they resume their sexual lives. Furthermore, Gochros (1992) suggested that gay positive men tend to neglect sex due to physical impairments, lack of a sex partner, lack of privacy at home, apparent or real loss of attractiveness, shame associated with sexual orientation, depression, lack of community support, and the dread of spread the virus. Moreover, Hoff *et al.* (1992) sustain that HIV positive gays tend to get emotionally involved with other positive men because of the belief that only people who have the same sero status can understand the emotional and social dynamics involved.

Tewksbury (1995) interviewed 45 HIV positive gay men and explored the influence of HIV on their gender identity and sexuality. His analysis focused on sexual risk taking along with social stigmatisation and personal commitment. He provided valuable insights in relation to the use of qualitative methods in the research of AIDS and the promotion of preventive measures (Sabo and Gordon 1995: 14-15). He stated that informants suffering from an AIDS related illness tend to completely abandon their sexual life which relates to their sense of helplessness in life. Yet, for some of his informants, this was an expected consequence of their ailment or age rather than forced celibacy, the absence of sexual activity passed unnoticed as health and daily life concerns become overwhelming. Medication side effects largely contribute to the decrease of sexual activity. Conversely, asymptomatic informants tended to remain sexually active. However, in both cases, the loss of sexual activity resulted in psychological stresses and changes of their understandings of masculinity and its performance. The dreadful prospect of transmitting the virus and the attempt to manage safe sex pushed them into "sexual self-imposed restrictions" that included "heightened levels of emotional intimacy, achieved in nonsexual interactions" (Tewksbury 1995: 236). Concurrently, changes in sexual activity significantly altered their gender identities, as "sex contributes to the definition of masculinity, and therefore, when sex is abandoned, both sexuality and masculinity need to be reconfigured" (Tewksbury 1995: 241).

Ariss (1997) found that sero conversion as a two-fold process of reconstruction and monitoring. First, PLWHA make sense of their personal experience and the shifting AIDS medical culture to regulate their physical body. Second, plugged into the intricate body of social relations, PLWHA confront social monitoring and regulation due to sero-conversion. And sexuality appears to be the point of convergence of both. Since "positivity disrupts desire" (Ariss 1997: 59), sexuality encompasses the utmost contested issue entangled in the self-restraint and social patrolling of the HIV positive. Actually Ariss (1997) suggested that PLWHA fear infection and losing control over their

relationships. He realised that they tend to keep others at a distance to sustain normality and prevent possible stigmatisation (Ariss 1997: 59). The disruption of sexual desire is of critical importance to HIV positive gay people due to the implications for their identity. In accordance with d'Emilio (1983), Ariss (1997) reported that disruptions in the sexuality of gay men are relevant because it is through their sexual identity that they construct their sense of identity and communal attachment.

As well, Adam and Sears (1996) argued that seroconversion fractures the grounds of sexual identity, in particular. In their research with HIV-positive people, they found that their informants must confront fears and anxiety related to their identity, emotions, sexuality and relationships. Some of the gay people that they interviewed felt trapped in the 'gay identity'. HIV obstructs their fantasies of "going straight", as informants felt as though they were "involuntarily outed" and confirmed the heterosexist stereotype "gay = AIDS" (Adam and Sears 1996: 63). Moreover, they discovered that for their bisexual and heterosexual informants, seroconversion implies a burden of understanding as to why 'normal' sexuality brought about infection. Nevertheless, regardless of sexual identity, initiation, continuation or resumption of sexual relationships became entangled with isolation, asexuality, fears of infection and discrimination, as well as with the difficulties of negotiating safe sex (Adams and Sears 1996: 74).

Concerning issues related to the sexuality of HIV positive women, Crawford *et al.* (1997) shed light on the difficulties that they faced in coming to terms with their sexual life. They drew on their ethnographic research with 27 HIV female carriers to highlight the two main problems their informants met when they resume their sexual lives. They found that HIV positive women were most likely identified as promiscuous and/or deviant and "the women reveal that they are understood by others and also by themselves in terms of these dominant discourses." (Crawford *et al.* 1997: 3). In addition, their informants expressed the moral dilemmas and paradoxes of disclosing their serostatus to enhance safe sex. They concluded that informants revealing their HIV status put them at risk of rejection and/or violence, while unprotected sex puts their partners at risk of infection (Crawford *et al.* 1997: 10).

In his ethnographic investigation involving 15 HIV-positive homosexuals, Halkits (2000) attempted to disentangle the relationship between body image and sexual behaviour among HIV-positive gay men. The report underlined the relevance informants place on developing and maintaining a muscular body, which allows them to 'pass' as HIV-negative and boosts their chances to meet sexual partners. In addition, the consumption of substances such as nutritional supplements, testosterone and more recently Viagra help them attain their version of masculinity. This version of masculinity in the realm of sexual relations demands sexual prowess or "raw," "uninhibited," and "manly" sex, which is more likely to occur with another HIV-positive individual as it lessens the worry or shame of transmitting the virus (Halkits 2000:

142-146). As well, Halkitis and Parsons (2003) stated that HIV-positive gay men looking for unprotected anal sex or barebacking, or sex without condoms, tend to define masculinity in terms of sexual prowess and suggested that barebacking might be related to the "AIDS-related fatigue" (Halkins and Parsons 2003: 375) or a way to oppose the safe sex messages that have infused the gay community. Also, barebacking is most likely to occur when an individual believes that a sexual partner is also HIV-positive, and when a connection to the internet is available, because he can anonymously access large amounts of information (Halkins and Parsons 2003: 375).

Little attention has been paid to the issues that Latin American PLWHA face when they resume their sexual lives. However in Latin America, rather than the enhancement of the quality of life of PLWHA, the literature indicates basic medical care still deems a primary concern. Pavia *et al.* (2004) interviewed a group of 22 HIV-positive Brazilian teenagers and found that the fear of discrimination makes them delay disclosing their serostatus to their partners and dates, or not do it at all. Informants complained that out fear, health care personnel are reluctant to engage in an open and straightforward conversation about sexuality, and those who acquire the virus sexually reported mistreatment when receiving gynaecological care and treatment.

Sample

Finding Latin Americans infected with HIV willing to participate in our project was the first problem we encountered. Fears of discrimination and invasion of privacy caused many people to be reluctant to participate in any activity that might lead to their identification as HIV carriers. This attitude is the first evidence of the unfavourable circumstances they face while living in Japan. Moreover, this situation casts doubts on the reliability and validity of the statistics and reports the Ministry of Health Labour and Welfare (MHLW) provides. The number of unreported HIV/AIDS Latin American cases must be greater than suspected.

In order to contact our informants we approached two NGOs, but our effort was fruitless. Then, a physician working at one of the biggest hospitals in Tokyo dealing with infectious diseases introduced us to 4 HIV-carriers. Afterwards, with the cooperation of a NGO based in Hamamatsu, city we contacted 5 more participants. Lastly, we were able to get 11 more informants by snowball sampling. We interviewed a total of 20 people. 15 are Brazilian *Nikkeijin* (Japanese descent), 8 HIV carriers and 7 AIDS sufferers. 3 are Peruvian *Nikkeijin*, 2 HIV infected people and one AIDS sufferer. One is a non-*Nikkeijin* HIV infected Brazilian, and the last one is a non-*Nikkeijin* Peruvian AIDS sufferer. All of them are men, and they are from 28 to 37 years of age. 7 of our informants identify themselves as homosexual and 3 of them are illegal residents in the country. In relation to their social class, 5 of them are white-collar workers and 15 blue-collar.

Foreigners and HIV/AIDS

The last MHLW's epidemiological update -September-December 2002- had a cumulative

total of 5,121 people living with HIV (PLWH) and 2,549 people living with AIDS (PLWA). Concerning the site of infection the document reports that the majority of the Japanese became infected within Japan (86% of HIV cases and 76% of AIDS patients) (Infectious Agents Surveillance Report 2002: 109). The report also highlighted the fact that the number of foreign PLWHA (People Living with HIV/AIDS) had decreased (Infectious Agents Surveillance Report 2002: 109). However, we suspect that this information is inaccurate. Rather than a decrease in the number of infections, the number of foreign people willing to be tested most likely decreased. Similar to Buckely (1997), we believe that for most foreigners do not get tested because of fears of job loss and deportation. The literature reports the case of a Brazilian worker of Japanese descent whose application for employment was rejected after he was identified as HIV positive. Testing was conducted without his consent, and it led to the indictment of his employer on allegations of invasion of privacy and illegal dismissal (Sugiyama 2001).

In addition, Miller (1994) and Buckely (1997) indicate that in contrast to nationals, foreign sex workers were most likely to be encouraged to undertake HIV-testing. Indeed, Jitthai and Miyasaka (1999) suggested that Thai commercial sex workers were reluctant to get tested because of financial problems, language barriers, and concerns about police harassment or deportation. Concerning the ethnicity of the foreign PLWHA living in Japan, reports from the MHLW do not provide information based on the country of origin. They present only the gross number of foreign HIV carriers. Yet, they highlight the fact that South East Asians have the highest rate of infection, followed by Latin Americans. (Infectious Agents Surveillance Report 2002: 110). The validity of this information is also questionable as Japanese health-care providers and employers are most likely to encourage the repatriation of foreigners suffering AIDS related illness (Imamura *et al.* 2001, Sawada *et al.* 2001a, b).

The Japanese health care system is well known for its universal coverage and its diverse treatment options. Problems arise when patients do not have a permanent job and when they do not have the means to afford the cost of individual insurance, especially when they have to cover the expenses of a degenerative illness, like AIDS related diseases. Moreover, the MHLW does not permit short-term visa holders, or people who have overstayed their visa, to join the National Health Insurance System; for them, medical expenses in Japan are extremely expensive (Komai 2001: 107). Thus, health providers are more concerned about unpaid medical bills, than about providing assistance on humanitarian grounds. Without regard for the patient's condition, there are hospitals that require the presentation of a valid visa and/or passport in order to provide health care (Imamura *et al.* 2000). There are also hospitals openly rejecting foreigners because of the belief that repatriation is the only option for HIV foreigners, since AIDS is a terminal disease and since the hospitals feel they should die in their homeland (Sawada 2001c: 134). Under these circumstances, foreigners tend to go to the hospital only when their physical condition is extremely serious. In 1999, Sawada

(2001c) conducted an investigation on the medical records of HIV foreign carriers, which included 14 medical settings in the Kanto region. The records of each patient over the previous three years were examined to investigate the relationship between being medically insured and the CD4 count. They found that the average CD4 count of those covered by medical insurance was over 290, and that most of them seemed to come to the hospital to preserve their immunity. However, the CD4 count of 45% of those without medical insurance was less than 50. It seems that most of them came to the hospital suffering from opportunistic infections. Moreover, Yamamura and Sawada (2002) in a longitudinal survey with HIV illegal aliens found that because of their irregular legal situation their access to medical treatment was restricted. They could barely afford the expenses, and they did not have information on available medical treatments. The condition of most patients suffering from AIDS related illness was critical when they attend the facilities for the first time. Most of them were afflicted with tuberculosis and *Pneumocystis carinii* pneumonia. Eventually, most of the AIDS patients died in Japan or in their homeland immediately after repatriation.

Method

Our participants were informed that the interviews were aimed at learning about their situation as PLWHA. The contents of the interviews were divided into three areas: disease-medication, social-support, and illness-sexuality. They were not necessarily presented in strict order but in a way such that the interviewee felt comfortable and the conversation ran smoothly. Moreover, we wanted to explore each of these areas in two interviews. In the second interview, we tried to expand upon the insufficient and/or unclear responses from the previous one. As a result, we had six encounters with each informant before or after they went to the hospital and at public places where they felt at ease and where the risk of being associated with AIDS was minimised. Each encounter lasted 60 minutes and they were recorded with the express consent of the interviewee. The period of investigation was from April to September, 2002 and during August, 2003 and 2004. In order to protect their privacy, we did not use the names of our informants.

In order to analyse our data we employed systemic networks – a device developed in linguistics that permits the translation of interview transcripts into the language of theory (see Halliday 1975; Kress 1976; Bliss et al. 1983). Through an induction-deduction iterative process, we produced conceptual categories that were meant to mirror the interviews' contents, and vice versa. Interviews were conducted in Spanish and Portuguese, transcribed in full and stored and coded with the assistance of the software package Ethnograph V5 (Coffey and Atkinson 1996). Rather than regarding the interview transcripts as directly representing reality, we used them as accounts of life or pieces of the "life history" (See Plummer 1995) of our informants, and in doing so, the explicitly meanings taken from each account were reported. However in considering our informant's accounts, we did not measure, counted or added them.

To analyse our data, we positioned ourselves within the framework of a feminist social theory. (see Ramazanoglu and Holland 2002). This framework allowed for a sound understanding of the consequences of HIV/AIDS in the lives of Latin Americans living in Japan and the meanings of their experience in relation to issues concerning justice, power, relationships, differences, and morality. The literature on medical treatment for PLWH shows that Japanese society is hierarchically constructed and that power relations permeate the ways nationals and foreigners interact. We question how and why such relations have been constructed throughout history, within and between cultures and in entanglements with other forms of power. In particular, we considered the relevance of ethnicity, citizenship and sexuality in our analysis. We think that sexual beliefs and practices are cultural constructions underlying the conventions of 'normal' heterosexuality. These conventions are likely to be used as strong arguments to sustain the discrimination against and the invisibility of people living with HIV and AIDS. Moreover, we believe that justice should not be understood only as a matter of the distribution of goods. Notions of domination and oppression should underlie a sound understating of justice, which implies taking into consideration issues concerning "decision-making, division of labour and culture" (Young 1990: 3).

Our main conclusions were made after our endeavours to account for contradictions, for the unexpected, and for absences and silences in the interviews. In order to cope with fallibility and subjectivity during the analysis of data, we emphasise both our own and the informant's reflections on HIV/AIDS, ethnicity, medical care and support, social class, sexuality and power, especially when confronted with material that cannot simply be 'read' either from the transcripts themselves or from our starting assumptions.

Embodying and HIV

Sexuality plays a key role in the ways our informants cope with the medicalisation of their identity, psychological distress and social pressure. Our analysis involves our informants' recounts of sexual experiences after being infected. For most of them the "HIV master status" (Adam and Sears 1996: 32) has become a means to regulate and patrol their sexuality. They find themselves stuck in the midst of a process of 'pedagogisation' that requires them to readjust their lives, and in particular their sexual lives. As Bell and Binne (2000:24) suggest PLWHA are rendered morally incompetent and infantilised. However, different from children who are constructed as pre- or asexual, and 'innocent' (Epstein and Johnson 1998: 1), the lack of innocence has made PLWHA ill. In addition, some of our informants realised that the main objective of this process of pedagogisation is not to enhance their wellbeing but to reduce the risk to 'healthy' people. So they have been asked to 'confess' (Foucault 1990) and offer a detail description of their sexual activity. This confession strategy blurs the borderline between private and public behaviour. For HIV negative people, sexual behaviour is a private issue, while for sero-positive it renders public scrutiny. In asking one of our Nikkeijin Brazilian informants why he stopped having sex, he answered:

Well... when knowing that you are positive get all shocked... and doctors emphasise that you should be extra careful to not pass it... you know to me they are more concerned about healthy people than yourself... the way they talk to you makes you feel that if you are done... at least don't kill someone else...

Interviewer: Did doctors ask you to stop having sex?

Interviewee: It is not that they tell you but you understand that... In a way you feel like a child when they talk to you... telling you all the things you should and shouldn't do... It is weird... Especially when you are not used to talk about something as personal as your sexual relationships... In a way you feel you have to confess what you've done... like when you are with a priest... (35 years old, legal alien, blue-collar worker, AIDS patient)

Similar to reported studies, we found our informants undergoing periods of celibacy and existential crises before resuming their sexual lives. This celibacy and crises period closely related to their medicalisation of life which is characterised by the misappropriation and mystification of medical knowledge and the dependence on doctors (Illich 1979). The pivotal role of the media in the dissemination of information, images and opinions (Kitzinger 1993) that link AIDS to death was vividly apparent in the ways our informants understand seroconversion. They tend to adopt the traditional understanding of "personal tragedy approach to disability" (Oliver and Barnes 1998; Burchardt 2000) which develops into the idea that they must live with the fear and uncertainty attached to the condition as with its physical symptoms (Sontag 1991). Indeed, our informants tend to think of HIV in terms of a "moral panic about their inclinations" (Barnes and Mercer 2003). They blame their sexual preference for their seroconversion and conclude that their 'deviancy resulted in their AIDS'. Hence they opt for the negation of sexuality and the fear of infecting their partners is overwhelming. As one of informants uttered:

It is just like starting all over again...

Interviewer: What do you mean?

Interviewee: When you are notified that the virus is in your body it is a shock... for a moment you don't know how to react but later on you start like seeing all your life in front of your eyes... It is the threat of death... You start thinking that you might die soon... and then ask yourself... Why me? ... and then gets all sad... depressed... For a while you try to find sense and direction... don't feel like meeting people... and of course the least think you want is to have sex... what's more you blame sex... You easily conclude that normal people who have normal sex don't get AIDS... you are afraid... (Nikkeijin Brazilian, 30 years old, legal alien, blue-collar worker, HIV carrier)

The postmodernist and social constructionist perspective in the study of HIV/AIDS has fostered the critical examination of common-sense, taken-for-granted knowledge, beliefs and practices. Under this gaze knowledge appears to be produced within specific historical, cultural and social time of periods (Burr 1995), and as Barnes and Mercer (2003) suggested HIV/AIDS deems an “inherently social process.” Problems arise when considering HIV/AIDS and impairment as a ‘mere discourse’ without presuming any necessary relationship to a specific body-mind condition (Fawcett 2000). The effects of medical treatment on the sexual lives of our informants illustrate that AIDS related impairment is more than a discourse and that a “sociology of the body where true bodies go missing is odd” (Connell 2001). Sex is not only a matter of a ‘discursive’ production, or something happening inside their heads (Dowsett 1996). Drug side-effects directly relate to the will of our informants to resume or stop their sexual lives. Most our AIDS informants go through periods of time where the medicine side-effects affect their arousal, body image and self-esteem. Indeed, medication causes a sense of disembodiment. As one of our informants expressed:

Well... I just feel so weak... sex doesn't even cross my mind... I have lost at least 10 kilos... my skin is all too dark... who do you think might have sex with me?... When I see my body I can tell that I am going bad and worse... I am not confident... I don't like how I look... I don't like myself... I don't think someone might like me... I feel my body like fading away... I don't recognise my body or better say my body doesn't recognise myself... (Brazilian, 29 years old, legal alien, white-collar worker, AIDS patient)

A partner's rejection and ostracism have also frustrated our informants' attempts to restart their sexual life. Our interviews suggest that although their processes of sexual re-initiation are contingent upon social support medication, they are not linear or univocal. However, our analysis of the interviews illustrates the relevance of masturbation as part of the beginning of self-recognition and reassurance to proceed and look for a possible sexual partner. Different from the literature, we find most of our informants look for sexual fulfilment and pleasure rather than emotional attachment or long term relationships. As migrant workers and/or individuals without proper visas, their place of residence largely depends upon job availability. They have to relocate constantly. Yet, in line with the literature, those looking for regular sex friends or partners try to find a HIV positive person like them. In talking about their re-embodiment experiences one of our informants without visas, reflected:

Believe me, this is like a 100 degree change... a change in my life... This was an interesting

contradiction. I am called positive because I've got HIV, but my vision of life was completely negative... full of fears... uncertainties... Rather than living, I was getting ready to die...

Interviewer: What made you change your vision of life?

Interviewee: You know you tend to think that everything is lost, but once I was taking a shower and suddenly I've got an erection... I start masturbating again... it is like rediscovering yourself, you know... then I ask myself... Why not? And then I decided to have sex again...

Interviewer: How did it happen?

Interviewee: I've met this guy... He is positive and has been fighting HIV for about 10 years... He has been a great teacher... I think now we are both enjoying sex... I was confronted: he told me that it was my choice... Live a life or live a death

Interviewer: So, you have a partner now, don't you?

Interviewee: No, not really... first I want to take it easy... and then it is difficult to have one if you have to move constantly, remember that I depend on brokers and my chances to find a job at the factory... Anyway, if I were looking for a partner... I think I would look for a HIV positive guy... (Peruvian, 31 years old, illegal alien, blue-collar worker, HIV carrier)

Sexual mores

As shown by the transcripts of our interviews one of the main issues our informants face involves the construction of sexual mores. Our analysis is consistent with Holland's *et al.* (1999: 458) argument concerning the prevalent definition of 'proper sex' as the act of vaginal penetration that relegates 'safe-sex' to the category of foreplay. We find most of our informants patrolled their sexual encounters based on a phallogocentric perspective of 'normal' and 'healthy' sexuality (Carpiano 2001: 135). For most of them and their partners, the penis renders into the focal point of sexual activity. Consequently, desire and pleasure entails an individual willing to penetrate and an individual expecting to be penetrated. Sex seems to be all about penetrations. Consequently, an adequate orgasm for both partners involves an adequate penetration, which is the main goal of arousal (Marshall 2002: 135). Most of our informants refer to 'real sex' as act of man penetrating a woman or another man. Indeed, for our homosexual informants 'real sex' is a matter of looking for a 'good top' and/or a 'good bottom'. Conversely, we find that some of our informants who refrain from practicing penetrative sex face the rejection of their partner(s). In being questioned about his safe sex experiences, one of our heterosexual informants answered:

I was always depressed without having sex, but I fear sex... Even if you know that safe sex is okay... I always ended up all too paranoid... I had to be extra careful, too nervous... that was not sex... everything was too planned... and your partner...

Interviewer: And your partner?

Interviewee: Yes, she gets too nervous too... you know... I think

that was the main reason... our relationship didn't work... I think to live and have sex with a positive guy you need to love him. (Nikkeijin Peruvian, 31 years old, legal alien, white-collar worker, HIV carrier)

Moreover, one of our homosexual informants suggested:

I think the main problem is that for most guys safe sex is not sex...

Interviewer: What do you mean?

Interviewee: In my experience, guys think that real sex is fucking... if you don't fuck... you are not having sex... I like kissing, petting, hugging and licking... but to be honest I am a bit clumsy to manipulate condoms... I get all nervous... lose arousal and can't keep going... (Nikkeijin Brazilian, 30 years old, legal alien, blue-collar worker, HIV carrier)

In addition, our interviews suggest that HIV testing might be reinforcing this phallogocentric perspective and the idea of 'real sex'. In line with Green and Sobo (2000) we find most of our informants and their partners setting a line to differentiate casual from regular sex. Our informants understanding of 'casual sex' compels safe sex, but it does not necessarily mean 'real sex'. In contrast, 'regular sex' tends to entail affection and HIV-testing because it means a long term relationship where the individual can get rid of condoms and enjoy 'a complete sex life'. Most of our informants have been rejected when they are asked to get HIV tested and have to reveal their serostatus to their HIV-negative partners. Hence, most of our informants engage in their sexual relations without revealing their serostatus. When we asked one of our informants about his reluctance to have a boyfriend, he answered:

It is not that I don't want a boyfriend anymore... if just that I think I have to wait until a good HIV-positive guy comes... I've tried several HIV-negative guys but... they turned down all the time... especially when they ask you to get tested...

Interviewer: What do you mean when you say especially when they are to get tested?

Interviewee: It is a common understanding... when you want to be emotionally involved with someone you need to get tested to have complete sex life...

Interviewer: What is a complete sexual life?

Interviewee: It is basically fucking without condoms... I think...

However, some of our informants refuse to give up to 'a complete sex life' and consciously engage in unprotected sex. Most of them appear to be fully aware of the risks of re-infection and drug-resistance but they still look for bareback playing. They actually look for other HIV-positive men willing to engage in barebacking. Our informants argue that medicalisation resulted in the feminisation of their identity.

Some of them realise that just like women, PLWHA are expected to give up the “powers of desire” (Snitow *et al.* 1983). As women are expected to observe the rules of a culturally sanctioned and silenced sexuality within the margins of femininity, PLWHA are supposed to lead a sex life within the margins of safe sex, monogamy or even celibacy, that does not permit a ‘complete sex life’. The metaphor “playing with fire” (Zavella 1997) is relevant to illustrate the attitude of some of our informants towards barebacking. Barebacking brings about a “hot,” “passionate,” “boiling,” “explosive” sexual pleasure (Zavella 1997: 393) which is like “playing with fire” or a difficult to stop and dangerous ‘game.’ One of our informants refers to his barebacking experiences as follows:

You know, I think doctors and stuff want us to be like women... a woman should not play around... they shouldn't have sex at all or have sex when they want but when men want... I know this sounds a bit foolish, and though things are changing... this idea that of women remaining virgin is still there...

Interviewer: Then, if you don't want to remain virgin, what do you do?

Interviewee: I am aware that this is like playing with fire... but after being turned down too many times... because of having the virus... I just want to have sex with HIV positive people... then we don't care... you don't have the worry of infecting someone... the chances to get rejected are slimmer... you can play... have hot sex... real sex... without the burden of condoms...

Interviewer: Condoms are a burden?

Interviewee: Yes, they are... you lose rhythm... just only when you try it without condoms you see the difference... at the end of the day, you realise that wearing condoms is like eating bananas without peeling... (giggling)

Interviewer: Have you heard of the risks of re-infections and drug resistance?

Interviewee: Yes, I know that I am playing with fire... but then you think what is the meaning of life if you can't do what you want to do... it is like living a life that it is not yours... I might sound a bit stupid but this is the life I want to live... anyway sooner or later you will be so weak to have even sex... (Brazilian, 28 years old, legal alien, white-collar worker, HIV carrier)

Realising sex

Most of our informants report the need of stimulants to have sex. *Gomeo* (N, N-diisopropyl-5-methoxytryptamine) and/or *rush or poppers* (amyl nitrate), and in some cases *Viagra*, have become an essential part of their “choreography of sexual practice” (Dowsett 1996). The use of *Viagra* encourages phallocentrism and those struggling with the side effects of HAART (Highly Active Antiretroviral Therapy) tend to prefer it. Yet, *rush* is most commonly used because it is cheaper and easier to buy and/or obtain. Most of our informants express concerns about the effects of these stimulants on their health, and in most of cases, their group of peers is their source of information. Talking about

sex with medical personnel is an issue, but talking about sex and stimulants is not even thinkable because of its association with illegality. In particular, those using *gomeo* recognise a double burden of discrimination: HIV/AIDS and drug use related intolerance. Some of our informants recognise that the stigma associated with drug use and disease can be devastating to their reputation. In reflecting upon his sexual experiences and consumption of stimulants, one of our informants stated:

You know... since I started taking medicines I can't keep my erections... then, *rush* and *gomeo* have been the answer to my problem... Sometimes I get Viagra from a friend... With my salary I can afford it...

Interviewer: Why erections are so important for you?

Interviewee: So important? Well, can you have sex without erections? ... I don't think so... well... I could use my fingers... but... I am not certain that that is sex... I don't know, though... Sometimes ... I have my doubts though...

Interviewer: Your doubts? Doubts about what?

Interviewee: About using *gomeo* I know that *rush* is okay... but don't know if you can take it along with the medicines... sometimes I feel so weak... but to have sex it is so better... It takes you to another dimension, I feel... I just can't help it... Having sex is just like having a new life... in a way you forget you are ill...

Interviewer: If you have doubts... why don't you ask to your doctor?

Interviewee: I think that is too personal... I don't think a doctor can help... I can't even talk about my personal stuff... Could you imagine? I can't What's more I think *gomeo* is not banned...

Interviewer: Then who do you talk about this?

Interviewee: Sometimes I talk to my friend... but I really don't want cos you know they are always gossiping... (Brazilian *nikkeijin*, 35 years old, legal alien, blue-collar worker, AIDS patient)

Our informants' accounts clearly illustrate what Bell and Binnie (2000: 4) refer to as a "moral topography of sexual citizenship." All of informants recognise that a city is the place where they can realise their sexuality. Regardless of sexual preference, in cities our informants can find sex partners easily. Indeed, cities provide them with sites of public sex, sex work and pornography. Different from our white-collar informants who tend to live in cities, the working conditions of most of our blue-collar informants force them to live in country side. Indeed, they have only restricted access to cities. Yet, most of them have found a means to travel regularly to big urban centres in order to have sex. In line with Bech (1997), we discovered that in cities our informants can be anonymous which allows them less social control. For our informants, HIV and/or their sexual preference have become "a particularly oppressive form of governmentality" that compels "self-policing and self-regulating" (Johnson 2002: 328). All our informants, in particular those living in country side, effectively take advantage of a strategy 'passing

as HIV-negative and/or heterosexual' to cope with discrimination and to enjoy their sexualities. When one of our blue-collar informants living in country side was asked about his chances to have sex, he answered:

Well, working in the country makes things difficult...

Interviewer: Difficult? Why?

Interviewee: First, because I don't want people know that I am HIV... Once your neighbours know you are HIV, it is hell, believe me... and it is difficult for a foreigner to have sex in parks and stuff...you know... there you see only Japanese and... they don't really like foreigners... I have seen them fucking without condoms in the park but if you come close to them they stop...

Interviewer: Then what do you do?

Interviewee: I save up some money and go to Tokyo... I go to saunas and stuff... there people are more used to foreigners... and they don't care about you being positive or something... in a way you hide yourself... have the sex you want and leave... no big deal... there are places where foreigners are still not welcome... but... honestly... I think for a foreigner with HIV the option is a darkroom in the city... (Peruvian *nikkeijin*, 31 years old, blue-collar worker, legal alien, AIDS patient)

For some of our informants, cities have also brought about the possibility to explore the world of prostitution. Two of our *nikkeijin* informants regularly offer sexual intercourse for pay because they can substantially supplement their income and comfort themselves with the sex they are looking for. Engaging in prostitution with Japanese men gives our informants the opportunity to behave as 'feminine' as they want. In their opinion, homosexual Latino Americans repudiate 'gay behaviour' as they have in mind the ideal of a "very straight gay" (Connell 1992), or 'strong macho guy' to define their understanding of gayness. In addition, their physical appearance and fluency in the Japanese language help boost their chances to find a possible client. In these experiences we found an idea of a 'tropicalised' sexual identity similar to the process Parker (1997) identifies as "the carnivalisation of the world". Our transcripts suggest that Japanese men prefer *nikkeijin* because they are 'hot' and give them a sense of 'security' as they closely resemble Japanese. Our sample does not include Japanese nationals however this insight in relation to the sexual behaviour of Japanese gay people needs further investigation. Safe sex for some Japanese people might still mean to avoid unsafe foreigners and have sex with Japanese only' (Feldman 2000: 58). Finally, for our informants, prostitution is the easier way to practice safe sex without being questioned about their sero-status. One of our informants explains why he engaged in prostitution as follows:

I entered into the business a couple of years ago... I

was looking for a boyfriend but Brazilians don't like feminine guys... also... when they know you are positive they bluntly reject you... Once when I was cruising in the park I've met a Japanese guy who gave me some presents after having sex... then he started giving me money... that's it...

Interviewer: So, you've gotten a Japanese boyfriend, haven't you?

Interviewee: Nah... most of Japanese I have sex with are married guys... They are rich, and have their own wife and kids... There is no romantic love in this business... It is a business and sometimes you make more money than in the factory... You know... Also, I have an advantage over other foreigners... because I look like Japanese and I am fluent in the language... and the Japanese don't like foreigners... and they think that Latin Americans are 'hot'...

Interviewer: What about safe sex?

Interviewee: That also... is not a problem as this is casual sex they know that... if they want to fuck they have to wear condoms...and you don't have to explain that I want condoms because I am HIV positive... anyway... I've found that different from Latin Americans who are into fucking... Japanese are more into getting sucked... then with a blow job... they are done and I get my money... (Brazilian *nikkeijin*, 32 years old, blue-collar worker, legal alien, HIV carrier)

Conclusions

The advent of antiretrovirals represents a major event in the provision of health care for PLWHA. Diversified treatments and the 'life histories' (Plummer 1995) of PLWHA pose a challenge to educational and medical professionals in relation to the delivery of treatments that enhance the quality of life of PLWHA. As for PLWHA who have access to medical treatment, AIDS does not seem to be a death sentence, and the ways some of our interviewees regard life and refer to their sexual experiences indicate that for them medical treatment means more than a physician "allocating more time to contemplate their own deaths" (Heaphy 2000: 165).

All of our informants acknowledge that resuming their sexual lives is a major event in coping with HIV. However, their accounts suggest that sexual related issues are barely considered in the "new discursive and administrative techniques for PLWHA" (Race 2001: 86), which includes their "new medicalised identity" (Heaphy 1996). Most of our informants realise that a medical facility is not a place where they can be advised about their fears and concerns related to sexuality. We contend that if concerns about the quality of life of PLWAH are not pure tokenism, sexuality related issues need to be included in the "new culture of health imperatives for PLWHA" (Race 2001: 87). Indeed, our findings suggest that sexuality deems a criterion to evaluate PLWAH's well-being.

In sustaining and revising their biographical narratives, our informants must confront dilemmas and tension in order to restart their sexual lives. Their accounts throw light on their strategies to exert the right to a sexual life and to decide upon their body in "the

flow of power” (Plummer 1995). They endure the power of medicalisation, the power of a sexuality hinging on phallogocentric perspective, and the power of a sero-negative society in a foreign country. The sexual experiences of the informants reveal how relations of power shape their identities and sexual experiences and how they resist them and creating new ones. Such relations of power reflect that their “sexual citizenship” (Evans 1993; Richardson 2000; Bell and Binnie 2000) is at stake. In their understanding the right to health sometimes seems to oppose the right to have sex, and most of them have to ‘pass’ as sero-negative to satisfy their sexual needs. This is particularly so when we consider why our informants might actively choose silence over disclosure, and look for cities where they can enjoy anonymity and sexual fulfilment. Our informants often silence their sexual preferences and identities to resist the overwhelming power of ‘sero-positivity’.

The accounts of our informants looking for the means of re-embodiment and resuming their sexual lives indicate the serious limits of a perspective that considers PLWHA within the margins of “medical reductionism” (Paterson and Hughes 2002: 38) and “the personal tragedy theory” (Oliver 1990). As a field of power relations, antiretroviral regimes and ‘re-education’ entail the political construction of PLWHA’s bodies and their “economic use” (Race 2001). As Bell and Binne (2000: 37) suggest in the case of “good and bad gay people,” we recognise that the economic use of the bodies of PLWHA nourishes the idea of ‘good and bad PLWHA’. Those unable or unwilling to comply with medical treatment and/or the safe sex principles are regarded as ‘bad’ PLWHA. As Heaphy (1998: 24) proposes in many cases PLWHA’s narrative of his/her own treatment can be in tension with the practitioner’s account of who the PLWHA ‘should’ be as a patient. Indeed, our analysis of interview indicate that the power of medicalisation largely supports the ‘pedagogisation’ of PLWHA make them like disable people, and encourages the process of “infantilisation” (Patterson and Hughes 2001: 32; Bell and Binne 2000: 24) of their bodies and sexuality.

However, the deployment of power is always imperfect, and Gramsci’s notion of ‘hegemony’ (Andermahr 1997: 93) helps explain how biomedical manipulative forces exert a hegemonic control of the bodies of PLWHA. Hegemonic control allows the creation of interstices. In line with Ariss (1996), we recognise the potential of alternative therapy for the production of sites of resistance and anti-discipline. Moreover, concurrent with Treichler (1991: 97), our findings suggest that the diversity in the approaches to HIV opens up the possibility of renegotiations of the relationship among biomedical experts, physicians, and HIV carriers. Indeed, these renegotiations seem to lead to debates about the role and ownership of the body, and our findings suggest that by means of sexual activity some of our informants contest the power of medicalisation and find a way to fight the virus. Sexual activity seems to enhance the benefits of medical treatment on the physical and spiritual well-being of our informants. However, we must, of course, beware of privileging these alternative accounts and

thereby slipping into what Atkinson (1996) describes as 'romantic constructions'. Through opening up of spaces by re-initiating their sexual life, some of our informants can critically engage with medical/scientific constructions of PLWHA and embody themselves; however these processes are not unproblematic.

Although most of our informants' understandings of their physical condition are based on more than an uncritical acceptance of the model of 'expert' medical knowledge, their psychological distress and fears to resume and maintain their sexual lives suggest that the primary source of support and information came from the clinic. Most of our informants unwittingly support the ideas related to deviancy and correctness in sexual behaviour based on pure 'medical prejudices'. Yet, we can infer that in terms of sexual behaviour their main source of information, if any, might be other PLWHA or the group of peers.

We agree with Heaphy (1998) and want our research to benefit to a certain extent our informants. We want our findings contribute a little to our understanding of the sexual life of PLWHA and provide the means for an educational intervention where our informants can break through the silence imposed by the pathological perspective of their identities and the medical disciplining strategies. The recounts of some of our informants suggest that the 'safe sex' discourse underpinning most of the HIV/AIDS educational interventions is losing validity. The challenge for educationalists is, then, to produce 'sensitive' interventions for PLWHA and their partners, regardless of sero-status and/or sexual preference. Interventions need to open spaces where participants can openly express their emotions and qualms concerning arousal, medication and disease, and where they can question the certainties related to their identities and sexual mores leading their lives. Should interventions do not yield 'healthier' behavioural changes, or 'considerable' improvements in the quality of life of PLWHA, at least they should create an interstice where participants can rationalise and attempt to offer a critical awareness of their own understandings and alternatives towards a life with quality grounded on rewarding sexual activity. Such an interstice must be removed from a moralising and legalising master narrative vis-à-vis sexual behaviour, ethnicity and migration. Hence, those reflections might help broaden the concept of sexual citizen different from that constraint to 'healthy and/or heterosexual couples.'

References

- Adam, B., and Sears, A. (1996) *Experiencing HIV: personal, family, and work relationships*. New York: Columbia University Press.
- Altman, D. (1994) *Power and Community. Organisational and Cultural Responses to AIDS*. London: Taylor & Francis.
- Andermahr, S., Lovell, T., and Wolkowitz, C. (1997) *A Concise Glossary of Feminist Theory*. New York: Arnold.
- Ariss, R. (1997) *Against Death: The Practice of Living with AIDS*. Amsterdam: Gordon & Breach.
- Atkinson, P. (1997) Narrative Turn or Blind Alley. In *Journal of Contemporary*

- Ethnography, 7 (3), 325-345.
- Barnes C., and Mercer G. (2003) *Disability*. Cambridge: Polity.
- Bech H. (1997) *When men meet. Homosexuality and Modernity*. Cambridge: University of Chicago Press.
- Bell, D., and Binnie, J. (2000) *The Sexual Citizen. Queer Politics and Beyond*. Cambridge: Polity.
- Burchardt, T (2000) The dynamics of being disabled. In *Journal of Social Policy*, 29 (4), 645-68.
- Burr, V. (1995) *An introduction to social constructionism*. London: Routledge.
- Carpiano, R. (2001) *Passive Medicalisation: The case of Viagra and Erectile Dysfunction*. In *Sociological Spectrum*, 21, 441-450.
- Crawford, J., Lawless, S., and Kippax S. (1997) *Positive Women and Heterosexuality: Problems of Disclosure of Serostatus to Sexual Partners*. In P. Aggleton, P. Davies, and G. Hart. (Eds.) *AIDS : Activism and Alliances*. London: Taylor & Francis, 1-14.
- Connell, R.W. (1992) A very straight gay: masculinity, homosexual experience, and the dynamics of gender. *American Sociological Review*, 57, 735-751.
- Connell, R. (2001) *Bodies, Intellectuals and World Society*. In N. Watson and S. Cunningham-Burley (Eds.) *Refreming the Body*. Hampshire: Palgrave, 13-28.
- Dowsett, G. (1996) *Practicing desire. Homosexual sex in the era of AIDS*. Stanford: Stanford University Press.
- Epstein, D., and Johnson, R. (1998) *Schooling Sexualities*. Buckingham: Open University Press.
- Fawcett, B. (2000) *Feminist Perspectives on Disability*. London: Prentice-Hall.
- Foucault, M. (1990) *The history of sexuality. Volumen 1. An Introduction*. New York: Vintage Books.
- Foucault, M. (1995) *Discipline and Punishment. The Birth of the Prison*. New York: Vintage Books.
- Gochros, H. (1992) The sexuality of gay men with HIV infection. In *Social Work*, 37 (2), 105-109.
- Gold, R.S., Skinner, M. J., and Ross, M.W. (1994) Unprotected anal intercourse HIV-infected and non-HIV infected gay men. *Journal of Sex Research*, 31 (1), 59-77.
- Green, G., and Sobo, E. (2000) *The Endangered Self. Managing the social risk of HIV*. London: Routledge.
- Halkits, P. (2000) *Masculinity in the Age of AIDS: HIV-Seropositive Gay Men and the "Buff Agenda."* In P. Nardi (ed.) *Gay Masculinities*. London: Thousand Oaks, California, 130-152.
- Halkitis, P. and Parsons, J. (2003) *Intentional unsafe sex (barebacking) among HIV-positive gay men who seek sexual partners on the Internet*. In *AIDS Care*, 15 (3), 367-378.
- Heaphy, B. (1996) *Medicalisation and Identity Formation: Identity and Strategy in the Context of AIDS and HIV*. In J. Weeks and J. Holland (Eds.) *Sexual Cultures. Communities, Values and Intimacy*. New York: St. Martin's Press. 139-160
- Heaphy, B. (1998) *Silence and strategy*. In R. Barbour and G Huby (Eds.) *Meddling with Mythology. AIDS and the Social Construction of Knowledge*. London: Routledge, 21-36.
- Heaphy, B. (2000) *Living with Death*. In J. Rutherford (Ed.) *The Art of Life. On living, love and death*. London: Lawrence and Wishart Limited, 164-182.
- Hoff, C., McKusick, L., Hillard, B., and Coates, T. (1992) *The impact of HIV antibody status on gay men's partner preferences: A community perspective*. In *AIDS education and Prevention*, 4 (3), 197-204.
- Holland, J., Ramazanoglu, C., Sharpe, S, and Thomson, R. (1999) *Feminist Methodology and Young People's Sexuality*. In R. Parker and P. Aggleton (Eds.) *Culture, Society and Sexuality. A Reader*. London: UCL Press, 457-472.
- Hughes, B. (2000) *Medicalized bodies*. In J. Rutherford (Ed.) *The Art of Life. On living, love and death*. London: Lawrence and Wishart Limited, 12-28
- Illich, I. (1979) *Limits of Medicine, Medical Nemesis: The Expropriation of Health*. Harmondsworth: Penguin.
- Johnson, C. (2002) *Heteronormative Citizenship and the Politics of Passing*. In *Sexualities*. 5 (3): 317-336.
- Kitzinger, J. (1993) *Media messages and what people know about Acquired Immune Deficiency Syndrome*. In Glasgow University Media Group (Eds.) *Getting the Message*. London: Routledge, 271-304.