

'Pueblo chico, infierno grande'

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‘Pueblo chico, infierno grande’

Community support and HIV/AIDS among HIV-positive Latin Americans in Japan

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ABSTRACT In this article, we present an aspect of our ethnographic investigation with HIV-positive Latin Americans living in Japan. In order to investigate the relationship between HIV/AIDS and community support among HIV carriers, we interviewed 20 male HIV-positive Latin Americans living in Japan. From April to September 2002 and in August 2003 and 2004, we conducted a set of six 60-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 non-government organization (NGO), and by snowball sampling. The analysis of the interviews indicates that informants did not find any community support. Informants were fully aware that the psychological pressure from the community affected negatively their CD4-count and viral load. Our analysis suggests three main issues concerning the ways our informants relate to their community: non-attachment, invisibility and under-representation. Serostatus, social class, sexual preference, ethnicity and legal status were referred to as barriers to freely associating within the community.

KEYWORDS citizenship ● community ● ethnicity ● legal status ● sexual preference ● social class

FOREIGNERS AND HIV/AIDS

The last Japanese Ministry of Health Labour and Welfare's (MHLW) epidemiological update – September–December 2002 – shows a cumulative total of 5121 people living with HIV (PLWH) and 2549 people living with AIDS (PLWA) in Japan (Infectious Agents Surveillance Report, 2002). Concerning the site of infection, the document reports that the majority of the Japanese have acquired infection within Japan (86% of HIV cases and 76% of AIDS patients) (p. 109). The report also highlights the fact that the number of foreign PLWHA (people living with HIV/AIDS) is decreasing (p. 109). However, we suspect that this information is inaccurate. It is our contention that rather than a decrease in the number of infections, what might be occurring is a decrease in the number of foreign people willing to be tested. In line with Buckely (1997), we believe that for most foreigners testing is entangled with fears of job loss and deportation. The literature reports the case of a Brazilian worker of Japanese descent whose application of 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 are most likely to be encouraged to undertake HIV-testing. Yet, Jitthai and Miyasaka (1999) suggest that Thai commercial sex workers are reluctant to be 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 of the MHLW do not provide information based on the country of origin. They present only the gross number of foreign HIV carriers; however, 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 healthcare providers and employers are most likely to encourage the repatriation of foreigners suffering AIDS-related illness (Imamura et al., 2001, Sawada, Edaki et al., 2001; Sawada, Hyodō et al., 2001).

The Japanese healthcare 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 degenerative illnesses, such as 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 healthcare (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 – hospitals want them to die in their homeland (Sawada 2001: 134). Under these circumstances, foreigners tend to go to the hospital only when their physical condition is extremely serious. In 1999, Sawada (2001) conducted an investigation on the medical records of HIV foreign carriers. The sampling included 14 medical settings in the Kanto region. The records of each patient over the previous 3 years were examined to investigate the relationship between being medically insured and the CD4 count.¹ 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 percent 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 is 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.

HIV/AIDS AND 'COMMUNITY'

In this article, we recount our interviews with 20 HIV infected people from Latin America living in Japan. This is the second part of our research on issues concerning the circumstances of Latin Americans infected with HIV in the archipelago. In the first part of our investigation, we discuss 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 medical second opinion. We recognize that informed consent and

communication in general between foreign PLWHA and the Japanese healthcare providers appears to be largely obstructed by fears concerning non-consensual disclosure; the self-perception migrants have of their alienation living in a foreign county; breaches of trust due to having experienced homophobia; fear of deportation, as some of them are illegal aliens; physicians' paternalistic attitudes; and unavailability of proper medical services directed to foreign people in Japan. Although issues concerning informed consent were 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 CD4 and an increase in their viral load² because of despair and anxiety. Psychological distress aggravates their illness. Due to an almost complete lack of support from the people around them, they are most likely to endure anxiety, depression and loneliness; that is why in this part of our research we aim to shed light on the ways our informants relate to other Latin Americans. We want to acknowledge the ways our informants receive help and support from their 'community'. We want to understand how they develop their social networks and how they are able to tackle distress with the support of people who are supposed to have similar linguistic, ethnic and cultural backgrounds.

The association of HIV/AIDS with community and support has ontological implications. Ever since the first AIDS patients were identified, family and community were central to the provision of care and psychological support. However, as Aggleton et al. (1999: 1) observe, family and community life often represent discrimination, ostracism and stigmatization, as their members do not always respond with support and understanding when they realize that one of them is sero-positive or has AIDS.

Community-related terminology has been incorporated into an official rhetoric that helps smooth the conflicts between governance and civilian rights concerning distribution of goods, and political participation and decision-making. References to 'community' are so embedded in the 'AIDS discourse' that communal involvement is considered to be an indicator of empowerment among the individuals affected by AIDS (see Patton, 1990). Indicative of this logic is the creation of a wide range of organizations. Altman (1994: 10) maintains that communal responses place considerable stress on the idea of a civil society, and the need to strengthen it, as a civil society is supposed to counterbalance the coercive elements of the 'political society'. The rationale of this way of thinking is so ingrained in policy making that financial support is assigned in accordance with the number of benefited communities. Most AID-related research, outreach, activism, prevention and care efforts are grounded on the idea of 'community' and the majority of organizations are aiming 'to mobilize the community',

especially in those countries where the appalling and devastating consequences of the pandemic have already affected even the basic social structures. However, rigidification and bureaucratization seem to be affecting the central system of most communal organizing. Professionalization and the boosting of most civilian activism have resulted in the strengthening of the ties with the patron, public or otherwise, and in the dwindling of the links with the community. As Altman (1994: 98) suggests, 'communal organizations have been rendered to neo-agents of the state because of their financial dependency, and the sense of communal ownership of the members has grown weaker'.

The situation in Japan vis-à-vis community organizing and HIV/AIDS is no different. Concurrent with Altman (1994), we recognize that for Japanese scientists, discussions on HIV 'basic science' occupy, as 'if by divine law', the first position, hence other topics, particularly those with a political and cultural content, appear to be peripheral. The 'community of scientists' is supposed to decide on the future of the pandemic in terms of 'risk' assessment of the 'vulnerable communities'. At a domestic level, this 'scientification' is noticeable at Japanese national conferences on AIDS. Although these conferences are designed to help Japanese face up to the reality of the spread of the virus among the identified 'vulnerable people', we believe that most of the research concerning AIDS in Japan does not fully represent their situation or the needs of the most affected people. There is always a scholar or researcher speaking on their behalf. It is our contention that those needs and demands the 'scientists' recognize as discrete variables with statistical significance are far removed from those that the concrete target population have. With the exception of lectures given by the so-called 'experts', regular speakers have only 7 minutes to talk, followed by a 3-minute question and answer session. This amount of time might be sufficient to present the findings of a quantitative study, but if you are presenting qualitative data it is almost impossible. Moreover, we have never heard a member of the so-called 'vulnerable communities' speaking of their own circumstances.

SAMPLE

Finding Latin Americans infected with HIV willing to participate in our project was the first problem we encountered. Fears of discrimination and privacy invasion led to a reluctance to participate in any activity that might lead to their identification as HIV carriers. This attitude was 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 MHLW provides. The number of unreported

HIV/AIDS Latin American cases in Japan may thus be greater than suspected.

In order to contact our informants we approached two non-government organizations (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 four HIV carriers. Afterwards, with the cooperation of a NGO based in Hamamatsu city we contacted five more participants. Lastly, we were able to get 11 more informants by means of a snowball sampling. We interviewed a total of 20 people. Fifteen were Brazilian *nikkeijin* (Japanese descent), eight of which were HIV carriers and seven of which were AIDS sufferers. Three were Peruvian *nikkeijin*, two of which were HIV infected and one of which was an AIDS sufferer. One was a non-*nikkeijin* HIV infected Brazilian, and the last one was a non-*nikkeijin* Peruvian AIDS sufferer. All of them were males and they were from 28 to 37 years of age. Seven of our informants identified themselves as homosexual and three of them were illegal residents in the country. With regard to their social class, five of them were white-collar workers and 15 blue-collar.

METHOD

Our participants were informed that the interviews were aimed at learning about their situation as PLWHA. The content of the interviews was divided into three areas: disease-medication, mental health support, and illness-sexuality. They were not necessarily presented in strict order but in a way with which the interviewee felt comfortable and so the conversation ran smoothly. Moreover, we tried to explore each of these areas in two interviews. In the second interview, we aimed 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 minimized. Each encounter lasted 60 minutes and they were recorded with the express consent of the interviewee. The period of investigation was from April–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 translation of the interview transcripts into the language of theory (see Bliss et al., 1983; Halliday, 1975; Kress, 1976). 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 (manufactured by Qualis Research Associates and distributed by Scolari; 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, we explicitly stated the meanings taken from each account. However, in considering our informants' accounts, we did not measure, count or add them.

Methodologically, we position ourselves within the framework of a feminist social theory (see Ramazanoglu and Holland, 2002). We think that this framework will bring about 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 consider 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. Yet, consistent with Young (1990), 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 understanding of justice, which implies taking into consideration issues concerning 'decision-making, division of labour and culture' (Young, 1990: 3).

Our main conclusions are 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 emphasize both our own and the informants' 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.

LATIN AMERICAN 'COMMUNITIES' AND HIV/AIDS

The experiences of our informants confirm that for them, community seems to be a place where their vulnerability increases. The relationship between the sero-positive and sero-negative Latin American communities living in

Japan illustrates the difficulties and implications of considering HIV/AIDS in terms of community, nation and globe. Based on our findings, we want to stress how much empowerment and exclusion are entangled in the notion of 'community'. Our analysis suggests three main issues concerning the ways our informants relate to their community: non-attachment, invisibility and under-representation.

Non-attachment

Developing a sense of attachment to their 'community' seems to be a complicated matter for our informants. Due to non-attachment, most of them face isolation, solitude, stress and depression. Their social networks are almost non-existent, and it is almost impossible for them to find emotional support. The adverse effects of this segregation are mirrored in their mental health, as their CD4 count tends to decrease when they are under stress. Based on the analysis of our interviews, we can report that our informants are reluctant to associate with other Latin American people due to: competition for employment, yearning for social mobility, differences in legal status, and 'cliquery' concerning social class and ethnic background.

They do not feel attached to their 'community' and they do not trust other Latin Americans in Japan. They regard other Latin Americans as rivals in terms of work opportunities. Helping a compatriot causes one to risk losing the attainment of a better job and of improved remuneration for oneself. Some of our informants state that associating with other Latin Americans might jeopardize their position in society because Japanese employers consider Latin Americans to be lazy, crafty and troublemakers. However, they experience ambiguous sentiments towards their 'community'. On the one hand, they need to be close to someone who is able to understand their language, but on the other, they prefer to keep a distance between them in order to secure their place in Japanese society. *Nikkeijin* are most likely to stay away from people of the same country of origin. They do so, because most of them have a proper visa and because they are most likely to be fluent in Japanese. They tend to lead a rather independent life and seem to be able to interact more easily with the Japanese. In asking how he gets along with Latin Americans, one of our *nikkeijin* informants states:

Not bad . . . hmm to be honest with you I prefer to keep myself away from them . . . I feel at ease if there is someone to talk with in Portuguese, but you know . . . in my experience Latin Americans are always looking for troubles . . . what's more Japanese tend to think that we are lazy, that we are always cheating . . . but what I hate most is that Latin Americans are very egotistic . . . they always want a better job, more money . . . I don't think you can always count on the loyalty of Latin Americans . . . it doesn't matter if they can take advantage of their friends . . . many people talk about the Latin American community but I

don't feel there is such a thing . . . I don't like saying this . . . but things are just like this . . . (*Nikkeijin* Brazilian, 35 years old, legal alien, blue-collar worker, AIDS patient)

For most of our informants their sense of affiliation to their community hinges on their employment, as they have to change their place of residence in accordance with job availability. The majority of our interviewees have lived in different places within the Japanese archipelago, or have returned to their country of origin several times. Non-*nikkeijin*, or illegal Latin Americans, are more likely to move to the countryside or to endure constant changes of location. On the other hand, *nikkeijin*, because of their legal situation, are most likely to have a permanent residence, and they are most likely to enter and re-enter the country. These frequent changes of residence render their links with the 'community' very weak. Their networks and friends are always temporary and subject to their mobility. For people without proper visas, things are much more complicated, as they have to relocate all the time. They look for places where they can be hired despite their legal status and for places to hide from the immigration authorities. White-collar *nikkeijin* tend to stay longer in the same place because they are more likely to enjoy the security of a permanent job.

Interviewer: How do you feel among Latin Americans?

Interviewee: I do really feel at ease, but you know it is difficult to keep your friends for long time . . . because of their job, or because they do not have visa, they have to move always from one place to another. Things are getting worse as the Japanese economy is going bad . . . Brokers can't guarantee employment always . . . It is like starting over and over again . . .

Interviewer: Then, how do you manage to meet up with Latin Americans?

Interviewee: There are these parties at Brazilian restaurants, you can drink and meet people but I can't say they are my friends . . . you don't talk about serious stuff to them.

Interviewer: Can you say that you are part of the Latin American community?

Interviewee: I don't think so . . . It is not like in my country where you can have friends and talk about your stuff . . . here is just like acquaintances . . . you never know when they are going to leave.

(*Nikkeijin* Brazilian, 30 years old, legal alien, blue-collar worker, HIV carrier)

In associating with other Latin Americans, social class is another issue our informants reported. Consistent with Tsuda (2003), we found that most *nikkeijin*, in particular Brazilian *nikkeijin*, tend to have attained higher levels of education, while non-*nikkeijin* are more likely to have attended only primary school. Most of the informants who hold a degree had a well-paid job in their country of origin but stagnation in the economy made them emigrate to Japan with expectations that their situation would improve. Although in Latin America they usually were entrepreneurs running their own business or white-collar workers, in Japan, most of them had become blue-collar workers. Their academic achievement or credentials are often

ignored and only those fluent in Japanese can aspire to desk jobs. These discrepancies in education and employment are significant and most of our informants tend to construct their social networks, regulate their lives and patrol their behaviour based on their schooling and work experience. Most of the blue-collar workers we interviewed have felt disregarded or discriminated against based on their work situation. Membership in the community based on social class aspirations is commonly referred to as a hindrance to the cohesion of Latin Americans in Japan. The accounts of our blue-collar informants show that regardless of sero-status, white-collar or even factory workers with a better financial situation assume that they are in a better position in society.

Interviewer: What about your gay friends?

Interviewee: I have very few. I don't think you can trust them most of them are very bitchy. For some reason, gay people always want to be the topic of the conversation. They are always lying . . . I know that we are all working-class people, but they act as if they are rich. They show off . . . they think they are trendy, fashionable, cool and even rich, even we know that we are all the same . . . we are factory workers . . . Of course you can't talk about serious stuff and I wouldn't talk about my sero-status to them.

(Nikkeijin Peruvian, 31 years old, legal alien, white-collar worker, HIV carrier)

To most of our informants, their legal status exerts great influence on their sense of belonging to a 'community'. Those without proper documents to reside in Japan are most likely to lose 'the sense of territoriality', or the sense of ownership and attachment to the land they inhabit. Fears of deportation or imprisonment cause them to endure nomadic lives. Their social life is almost non-existent, and their chances to attain psychological support from their peers are slim. Our informants without proper visas suggest that in general Latin Americans prefer not to associate with someone who is 'illegal'. They do not want to be mistaken for 'criminals'. The relatives, friends and neighbours of our informants without proper visas have suffered intrusive visits from the police and immigration authorities, and even harassment when the police realized that one of the members is undocumented. Matters are further complicated for those who have disclosed their sero-status. The combination of sero-positivity and illegality have made the life of some of our informants miserable and their links to their community non-existent; they have to bear constant changes of residence and their feelings towards Latin Americans tend to be unfavourable.

Interviewer: Why do you feel very lonely?

Interviewee: Because, it is difficult to find friends.

Interviewer: Why is it so?

Interviewee: First, because I have to move very often because I don't have a visa. This time I have lived longer in the same place but I would rather continue moving because the police might find me. It is always a risk to go

out and be asked to show my ID. Once they discover that you are illegal it is very harsh even for the neighbours . . . authorities start coming and they are very inquisitive . . . sometimes they even harass my friends. Police tend to think that we are all criminals . . . Then I've found that Latin Americans don't want to be close to illegal people . . . I had some friends in Gunma and I used to hang out with them once a month, but when they knew I didn't have a visa . . . they kept avoiding me, I have telephoned them . . . as usual . . . but they don't pick up the phone anymore . . . they don't even try to contact me . . . I don't see them any more.

(Peruvian, 31 years old, illegal alien, blue-collar worker, HIV carrier)

As we have argued, the ethnic origin of our informants strongly influences their sense of attachment. They tend to associate with other Latin Americans based on their lineage. Although most of them are blue-collar workers, the *nikkeijin* are most likely to assert a different position in the society since they claim to have a better understanding of the 'Japanese way of thinking and behaving'. In front of Latin Americans, *nikkeijin* usually insist that they are 'Japanese', while in front of Japanese people they assert their Latin American origin to differentiate themselves. Those of non-Japanese descent are most likely to experience a lack of communal membership vis-à-vis other Latin Americans residing in the country. Some of our informants have also experienced discrimination because of the colour of their skin. In the opinion of our informants, despite the fact that most Latin Americans are of mixed ancestry, those who have a 'Caucasian' physical appearance or can claim to have a European background tend to disregard those whose features seem to fit the stereotype of an indigenous or black person.

Interviewer: What about Latin-Americans?

Interviewee: It is also very difficult . . . In my experience Latin Americas can be damn mean and racist . . . The *nikkeijin* are not that racist but they can be very conceited sometimes . . . they think they know everything about Japan . . . because they speak better Japanese . . . in any case . . . the worst are those South Americans who believe they are Europeans just because they have blue eyes and are white . . . Some of them even lie to the Japanese or other friends . . . I've seen many guys who said they are Italians . . . but we all know they have just an Italian family name . . . You know, to be honest . . . I am tired of them . . . That's why I don't go to bars much . . . It is not fun to go to hear all that bullshit . . . They can be really mean . . . believe me . . .

(Brazilian, 28 years old, legal alien, white-collar worker, HIV carrier)

Invisibility

The second serious issue our informants report in relation to living in a 'community' entails social invisibility. HIV-positive and homosexual Latin Americans are supposed to be part of the 'community', but they are not visible. In this particular case, social invisibility refers to the possibility of

coming out as a HIV-positive individual, or as a person who feels attracted to people of the same gender without being afraid of ostracism. Due to this lack of visibility, they are most likely to face blatant violations to their rights. Based on our interview transcripts, we recognize that this social invisibility is largely attributable to contempt or animosity towards their HIV-positivity and their sexual preference. We recognize three sources of phobia: HIV phobia or the hatred towards HIV-positive people; straight-homophobia or the condemnation of heterosexuals of any male's behaviour considered to be non-masculine; and queer-homophobia or the condemnation of homosexuals of those 'gay people' who are too 'girlish'. Consequently, most of our informants are thwarted in their attempts to have an 'open life' as HIV carriers or homosexuals.

The majority of our informants have felt disregarded because of their sero-status. HIV-negative Latin Americans in Japan tend to disapprove of HIV-positive people and they openly reject them. For our informants, HIV-phobia, rumours and even violence have made their living in a 'community' an appalling experience. Rife gossiping and extreme propinquity are two of the main disadvantages of dwelling in a neighbourhood surrounded by Latin Americans. For our informants, it is very difficult to have a sense of privacy and personal identity while being among people from the same ethnic and cultural background. Most of our informants report disquieting experiences and have suffered a humiliating seclusion and violence because of their sero-status. Due to this appalling circumstance, most of them prefer to be discreet. They are reluctant to participate in any activity that might involve disclosing their sero-status. Furthermore, some of them even have had to change their place of residence to combat the terrifying effects of seclusion and isolation on their health. In the experience of our informants, most Latin Americans in Japan react with contempt towards HIV carriers.

Interviewee: It's disheartening that outdated perceptions about HIV and AIDS remain unchanged today. I believe that this shows that the Latin Americans' activities to educate the public about the true nature of the disease have been only superficial.

Interviewer: What do you mean?

Interviewee: hmm . . . most Brazilians here are very aggressive. They don't like HIV people, I know.

Interviewer: How do you know that?

Interviewee: Most people are working-class people. They did not go to school, they have no information about AIDS; even if they have, it is difficult for them to understand that they can't get infected by associating with a HIV carrier.

Interviewer: Have you experience discrimination?

Interviewee: Yes . . . Once they know you are HIV you are out of the circle. I don't think they are people you can rely on.

(Brazilian, 29 years old, legal alien, white-collar worker, AIDS patient)

Fear of contracting HIV due to ignorance about the ways HIV can be transmitted is the main cause of most of the discrimination against our informants. However, in general, the association of HIV with sexual deviancy appears to be the main cause leading to discrimination. In the opinion of most of our informants, HIV-negative people usually think that infection is the product of deviant or promiscuous sexual behaviour. In this sense, HIV-positive men are immediately associated with homosexuals and HIV-positive women are most likely to be identified as commercial sex workers (see Crock, 2001).

Due to this common misunderstanding, most of our participants have to cope with, regardless of their sexual preference, straight-homophobia. As Gilman (1989: 98) suggests, the appropriation of the iconography of AIDS is not random, it is rather the perception that the sexual orientation of people with AIDS is determinant. Of course, ignorance about the ways HIV can be transmitted is always one of the main components of the AIDS stigma. However, interviews suggest that most of our informants have been discriminated against because of the association of the syndrome with homosexuality. Our transcripts further indicate that in the common understanding of Latin Americans in Japan, people who feel attracted towards people of the same gender are abnormal, perverted or indecent.

Interviewee: I am looking for friends . . . but . . . I think Latin Americans, in general, do not like gay people. And if they know you are positive they don't want even to get closer to you. You know it is very difficult to find Spanish speaking people willing to be your friend . . .

Interviewer: Why do you think so?

Interviewee: For instance, once at party I was with my friends and a group of guys started mocking and harassing us. We didn't do anything wrong we were at my friends place and we were just dancing. We didn't know them and they started shouting insults . . . very derogatory comments. They even called as *sidosos* (the Spanish word for people living with AIDS) . . . Gosh! I really wanted to kick their ass . . . finally they left the place . . .

(Peruvian, 28 years old, legal alien, blue-collar worker, AIDS patient)

In accordance with the opinion of our homosexual informants, gay Latin Americans draw on their culture of *machismo* to produce a gender regime to patrol their own and others behaviours. Concurrent with Prieur (1998), we found that, for our informants, standards of masculinity are customarily used to refer to what a 'masculine homosexual' is. The majority of them 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. Based on their sexual preference, most of our informants have felt rejected, because they appear to be too 'gay'. Butler's (1990) assertions of performance and performativity of gender are very useful in explaining the ways our informants control their demeanour. Concurrent with Parker (1999) and Lancaster (1995), they do not seem to care about men who have

sex with men as long as they are willing and able to perform as ‘men’. Intercourse with people of the same gender does not represent a threat, does not menace; a man performing like a girl does. In this respect, our informants appear to be regulated by ‘the general pressure to conform to hegemonic masculinity that is exerted by the surveillance power of the “male-in-the-head”’ (Holland et al., 1998: 28). They have experienced homophobia both from people sharing their sexual preference and from others. We use the term queer-homophobia to name the hatred of homosexual people for ‘effeminate performance’. Ward (2000) refers to it as ‘queer sexism’. Most of our informants associate with other homosexuals based on certain ‘regimes of gender’ (Dowsett, 1996). This regime renders their sense of belonging to their community contingent upon their understandings of same-gender relationships and their understanding of the boundaries between ‘acceptable’ masculinity and femininity. Most of our informants have suffered discrimination, or they themselves discriminate against others because of their fear of being identified as homosexual. This fear appears to have a common origin: the assumption that the desire for people of the same gender is a perversion and the assumption that homosexuals are prone to acquire and spread HIV because of their ‘vicious’ sexuality.

Interviewer: How do you relate to Latin Americans around you?

Interviewee: Frankly speaking I keep myself away from them. They have a lot of issues, especially concerning sexuality. If you are gay it is very difficult to be open. They always care about what you do, where you go and so on . . . In my experience Latin Americans are very bigoted.

Interviewer: What makes you think so?

Interviewee: If you are at a gay party or if you are in the gay area it is okay, you can behave as you want, otherwise you have to pretend. It is not that I want to be flamboyant . . . but . . . they are always speaking ill of effeminate guys in the neighbourhood. You have to behave like a straight guy. They disregard homosexuals by calling them *too gay*. A guy who used to hang out with me told me that he didn’t want to do that anymore, because I was *too gay*.

Interviewer: Why do you think he said so?

Interviewee: Because he is afraid of being identified as homosexual . . . it is a bit stupid to me but I think this gay is very macho type . . . they like only gays who look like very masculine . . . hmm . . . it is also because they think that if you are *too bicha* (queen) . . . they tend to think you have AIDS.

(Brazilian *nikkeijin*, 35 years old, legal alien, blue-collar worker, AIDS patient)

Under-representation

Currently, it is generally assumed that people living with HIV and AIDS in Japan should have a means to talk about their situation, protect their rights and represent their communal and individual interests. Supporting ‘community’-based PLWHA organizations is a premise of representation;

thus, community-based organizations are supposed to represent those suffering from AIDS. Unfortunately, as time has passed, community initiatives appear to have become obsolete in Japan. Our interviews affirm this point and most of our informants report the harsh reality of living with HIV in a foreign country, with no opportunity to speak of their situation. Although they are provided with medical treatment, most of them do not have access to a community organization that will represent their rights before the Japanese government and/or its representatives. They do not have a role in communal activism, as most of the communal activism is run by HIV-negative people, heterosexual, and *nikkeijin* people. Our interviews shed some light on the issues affecting the lives of our informants concerning under-representation vis-à-vis sero-status, sexual preference and sexual rights.

Most of the efforts of our informants to gain representation have not been fruitful, as most of the AIDS activism among Latin Americans in Japan is run by sero-negative people. In addition, their hectic lives, as blue- or white-collar workers, and their often poor Japanese language skills make the probability of negotiating with Japanese authorities in order to obtain assistance very low. There is always someone speaking on their behalf. Someone might have very 'good intentions' but, despite having the means to make them visible, he or she will decide to silence their voices. Little is known about the circumstances of HIV-positive Latin Americans in Japan, as surveillance encompasses only the approximate number of foreigners infected with HIV or suffering AIDS in Japan, and their needs, concerns and preoccupations have been barely investigated.

Interviewer: Why do you think it is so difficult to organize Latin Americans?

Interviewee: I think people always want to take advantage of the situation.

Interviewer: What do you mean?

Interviewee: It is very strange to me that here people who belong to the organizations fighting against AIDS are all HIV-negative. In my country most organizations have HIV-positive people in campaigns . . . I think people here are more into the business, I believe they are into the money they can get out of the HIV carriers.

Interviewer: What makes you think so?

Interviewee: I know people who are getting money from the Japanese to help carriers but they do nothing . . .

Interviewer: Can you be more specific?

Interviewee: I'd rather not; I don't think I should talk about it.

(Peruvian *nikkeijin*, 31 years old, legal alien, AIDS patient)

Our accounts indicate that the informants who are willing to lead an open 'homosexual' life as HIV-positive people in Japan have to tackle the strongest criticism and under-representation. Most of them have endured the combination of HIV-phobia and straight-/queer-homophobia. They have attempted to 'mobilize' their community in order to raise HIV/AIDS

awareness and to enhance sexuality education; however, their endeavours have been unsuccessful. They have been rejected by the HIV-negative people coordinating activism among Latin Americans. Our informants feel that these coordinators are taking advantage of the pandemic to make a living and their concern is concentrated on obtaining financial profits rather than helping people in need. Some of our informants also tried to mobilize homosexual Latin Americans living in Japan, but in line with one of the activists quoted in Parker (1999) we found that most men are too busy looking for 'fun' to get involved in HIV/AIDS education campaigns. Grouping and divisions concerning social class, ethnicity and legality are evident among the 'homosexual community'. In other words, among homosexual Latin Americans living in Japan, 'community' attachment and gathering is extremely problematic because of differences concerning sexual identity, sexual practices and preferences, as well coming-out experiences as homosexual or as a HIV carrier.

Interviewer: How do you get along with people from Latin American?

Interviewee: I really don't get along with them. I don't think there is such a thing called community. If it is to have fun they are always ready, but if you need help they are useless, what is more because of the community I had to change jobs.

Interviewer: Why did you have to change jobs?

Interviewee: I did not really want to but when people in my neighbourhood knew that I was HIV-positive it was very difficult to live there. They didn't want even to talk to me. So I had to find a new job and move.

Interviewer: Have you tried to find help at an NGO?

Interviewee: I've tried to do that once, but it didn't work.

Interviewer: What do you mean?

Interviewee: I wanted to participate and try to organize the gay Latin Americans having HIV, but they said to me that they were basically into prevention . . . to me it seems that they didn't want to get involved with gay people . . .

Interviewer: Then why don't you try to organize people and do something yourself?

Interviewee: You know, it is very difficult, if you work 10 or 12 hours a day to find the time to organize people . . . Besides, I don't speak fluent Japanese . . . it is very difficult to get money from the Japanese . . . if you don't speak the language . . .

(Brazilian *nikkeijin*, 32 years old, legal alien, HIV carrier)

The last matter concerning under-representation relates to HIV-positivity and sexual life. Based on our interviews, we found that it is a common understanding for most Latin Americans in Japan that a person infected with HIV should be celibate; otherwise he or she poses a threat to their community. It is clear that most of the activism and campaigns to protect the rights of PLWHA have focused on treatment accessibility, and have barely drawn attention to their immune-depression and their rights as

sexual beings. Although most HIV-positive people lead full lives and are willing to exert their right to have a sexual life, they are represented as 'asexual' beings, even if they do not have visible symptoms of AIDS or are just HIV carriers. It is our contention that AIDS activism and education in Japan is directed towards hindering the spread of HIV by placing the emphasis on HIV-negative or 'healthy people' and, as Patton (1990) suggests, leaving aside those who are more in need of attention, care and support.

Interviewer: Have you come out as a HIV carrier?

Interviewee: Yes, I have, well, but it is not because I was thinking of coming out . . . Once I wanted to start up a relationship with a guy, and I wanted to be honest with him. I told him that I was positive. Then everything collapsed. I was turned down. He didn't want to talk to me anymore. The worst is that he said to his friends that I am positive. After that I can't go to bars or associate with gay people because they think I am dangerous . . . Once I was confronted . . . they said to me that it was not correct to try to find a healthy partner . . . for gay infected people there is nothing but seclusion and celibacy . . .

Interviewer: Do you have a partner right now?

Interviewee: No. And . . . I think for the time being it is okay if I don't have one. I am still readjusting to my new life. I believe . . . for a HIV carrier is very difficult to have a partner, especially among Latin Americans. You know the saying 'Pueblo chico, infierno grande', [a closer expression in English is 'A small town is a place where everyone knows whose check [UK: cheque] is good and whose husband is not'] describes perfectly the situation of gay Latin Americans in Japan. I just keep avoiding them . . .

(Brazilian *nikkeijin*, 34 years old, legal alien, blue-collar worker, AIDS patient)

CONCLUSIONS

The 2004 UNAIDS report on AIDS (UNAIDS, 2004) reflects the damage that HIV is still causing, in particular to people in developing nations. Consequently, the number of politicians who consider AIDS as an issue of national security is increasing. Sadly, the political geography of HIV indicates that the borders between the First World and the 'other worlds' are unmistakable. In industrialized societies, HIV carriers are regarded as suffering a chronic illness, while those in the rest of the world struggle to access minimal treatment.

The UN report also suggests that despite the fact that few Latin American countries provide complete antiretroviral treatment to PLWHA, the number of infections seems to be declining. Conversely, all Japanese citizens and legally settled foreigners in the country are entitled to medical treatment, but the number of HIV carriers is still increasing to a point that

it is called 'Japan's AIDS time bomb' (Head, 2004). However, our findings suggest that AIDS continues to loom large over Latin America and Japan. In both areas, the quality of life and the rights of PLWHA are still pending. In spite of our concentration on Latin American PLWHA living in Japan, we can infer that for Latin American as well as Japanese policy makers, deterring the spread of the virus among 'healthy people' and providing medical treatment for the infected have been the main concerns. Thus, drug accessibility and educational campaigns have been the priority. However, such campaigns seem to be problematic. Our investigation shows that the differentiation between HIV-positivity and -negativity is concrete, as most HIV infected people might be facing discrimination and isolation.

Our findings indicate the difficulties Latin Americans living with HIV/AIDS face in interacting with people from the same region in Japan and how community-based organizations fighting AIDS are not necessarily coping with this reality. Through the eyes of our informants we realize the complexity of any attempt to improve the quality of life of HIV carriers from Latin America living in Japan, as well the need to improve the 'sexuality education' – HIV/AIDS education included – of both seropositive and negative Latin Americans. The heterogeneity of the 'Latin American community' in Japan also has to be taken into consideration when organizing, campaigning and educating people about HIV/AIDS. Moreover, effective strategies that are cognisant of the mobility of these populations need to be developed. Entwined notions such as mobility, illegality and infection have to be revisited to produce innovative materials based on the real hardships Latin Americans in Japan currently endure.

Our findings reflect the inapplicability of terms such as 'vulnerable' populations or 'community' to refer to AIDS sufferers, as they overlook power relations within and between the communities and diversity in terms of identity among their members. It is our contention that on its own, 'vulnerability' seems to be a good option, but in practical terms it tends to operate as a synonym for the discredited term 'risk group'. People living with HIV have a personal history, a background that includes social class differences, ethnicity, and sexual preferences that determine the ways they relate to people of the same group. In addition, the use of the phrase 'vulnerable groups' seems to reinforce discrimination and denial, as Latin Americans who do not perceive themselves as 'deviant' tend to believe that they are safe and that AIDS is a syndrome affecting 'others'. This 'othering' process tends to produce 'vulnerability' among both HIV-positive people and others.

It is our contention that there is invisibility and under-representation among Latin Americans suffering HIV and AIDS in the organizations campaigning for HIV/AIDS in Japan. That is why we are certain that any attempt to improve their circumstances entails the recognition of the diversity among them and the deeper investigation of their needs.

Authorities need to stop thinking 'by proxy' when they refer to Latin Americans with HIV or AIDS. In order to hear their voices, feasible mechanisms that guarantee their participation in support organizations must be put in place. The promotion of a sense of ownership in organizing the 'community' will enhance agency among PLWHA from Latin America in Japan. The pernicious influence of differences concerning ethnicity, legality, social class aspirations, HIV-positivity and sexuality within the 'community' might be reduced by promoting communal ownership and 'fair' resource allocation. 'Othering' within the community needs to be expunged. Legal, financial and logistical structures must be created or modified to make Latin Americans living with HIV and AIDS understand that communal participation is not something that someone does for them. They need to do it for themselves. In order to mobilize the community, stimuli coming from within the community are most likely to render positive results.

In addition, research on sexuality, citizenship, and HIV-positivity needs to be encouraged within the country itself, in order to improve the quality of life of Latin Americans living with HIV in Japan. HIV-positive people and their partners, regardless of sero-status, should be provided with accurate and complete information about sexual performance and HIV. Our interviews suggest that depression is closely related to discrimination based on sexual preference, citizenship, and sero-status. Tackling depression might help diminish immune-deficiency.

Finally, in order to attain a comprehensive understanding of the circumstances of PLWHA in Japan, to enhance their quality of life and to promote political reform, our findings need to be included in a comparative study with national and foreign HIV carriers with citizenry and ethnic backgrounds as the main axes.

Notes

- 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.

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