

The Experience of Stigma: People Living with HIV/AIDS and Hepatitis C in Argentina

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Abstract

This article compares the experiences of people living with HIV/AIDS with those living with Hepatitis C in Buenos Aires, Argentina. In both cases, people learn to live with the illness, and get to know about symptoms, treatments, diagnoses, and future perspectives. In the end they become “experts” on the matter. At the same time, they are forced to deal with the “synergy of stigmas” associated with deadly diseases, and in most cases related to sexual behaviors and lifestyles historically stigmatized. Selected by availability we interviewed 27 people living either with HIV, Hepatitis C, or both; and 20 health care professionals. Through out this paper we trace similarities, differences, and articulations in terms of the management of the information on homosexual identity, being drug users, and living with HIV/AIDS and Hepatitis C. We analyzed these issues as non-evident traits of discreditable individuals, which allow a relative concealment and their fears on revealing their secrets.

Keywords: HIV; Acquired Immune Deficiency Syndrome; stigma; Hepatitis C; Argentina.

La Experiencia del Estigma: Las Personas que Viven con VIH/SIDA y Hepatitis C en Argentina

Compendio

Este artículo compara las experiencias de personas que viven con VIH/SIDA con las de personas con Hepatitis C en Buenos Aires, Argentina. En ambos casos, las personas aprenden a vivir con la enfermedad y a conocer sobre síntomas, tratamiento, diagnósticos y perspectivas futuras. Al final se convierten en “pacientes expertos” en la materia. Al mismo tiempo son forzados a manejar la “sinergia de estigmas” asociadas con enfermedades letales, en la mayoría de los casos relacionados a conductas y estilos de vida históricamente estigmatizados. Seleccionados por disponibilidad, entrevistamos 27 personas que viven con VIH, con Hepatitis C o con ambas, y a 20 profesionales de la salud. A través de todo el trabajo trazamos similitudes, diferencias y articulaciones en el manejo de la información sobre la identidad sexual, el uso de drogas y la vivencia con el VIH/SIDA y la Hepatitis C. Analizamos estas cuestiones como rasgos no-evidentes de individuos desacreditables, lo que permite una relativa simulación, y los temores que dichos individuos albergan sobre la revelación de sus secretos.

Palabras clave: VIH; Síndrome de Inmunodeficiencia Adquirida; estigma; Hepatitis C; Argentina.

In this article we compare the experiences of people living with HIV/AIDS with those living with Hepatitis C. Both illnesses are chronic and serious; they are treated more or less effectively with medication, and are characterized by uncertainty. The first one has been loaded with different meanings, frequently negative, since very early on; the second one was almost unknown to most people, who would mistaken it for common hepatitis. To compare daily life and how to manage the illness in people living with HIV/AIDS to the lifestyle of those living with Hepatitis C, seems an interesting exercise to emphasize the social connotations that

distinguish and imply stigma for HIV/AIDS, and the apparent lack of symbolism of Hepatitis C.

In both cases, people learn to live with the illness, and get to know about symptoms, treatments, diagnoses and future perspectives. In the end they become “experts” on the matter. At the same time, they are forced to deal with the “synergy of stigmas” (Parker & Aggleton, 2002) associated with deadly diseases, and in most cases related to sexual behaviors and lifestyles historically stigmatized.

Our proposal will describe and analyze life with one or both pathologies, emphasizing the synergy of stigmas, the different ways social discrimination is manifested (directly or indirectly, executed or anticipated, at different levels and spaces), and the learning or “expertise” processes acquired in order to live with the disease and deal with its negative social consequences.

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Background

During the 1980's in Argentina, HIV/AIDS was considered an epidemic that affected primarily homosexual men; in the 90's the main mean of transmission was through injected drug use. Today the panorama reflects a relative predominance between heterosexual contact and the other two categories. That's why we found that our research sample was infected through one of these different ways. In addition to some of the injection drug users (IDU) that got infected with Hepatitis C, there were others that got infected with the virus presumably by sexual contact, a blood transfusion, or by unknown reasons.

In this country, antiretroviral treatment is universally available but treatment for hepatitis is not widely guaranteed. In 1991 a law to protect people living with HIV was approved, making the fight against AIDS even stronger. It was a law that includes access to treatment at the public health sector. Two laws approved in 1994 and 1995 make HIV treatment coverage mandatory for both the public and private health insurances. This is why in 1997 when HAART² started in Argentina, we were one of the few middle class countries with universal health insurance coverage for HIV treatment. At the same time, during the last two decades of fighting against the epidemic, a true national social movement was built around HIV/AIDS issues and the most vulnerable population groups.

The situation of people living with HIV makes evident the social and political complexity that relies in discrimination and social acknowledgement, what we could name as "incoherence". During the 80's and early 90's, the law protected people living with HIV, even with positive discrimination measurements, while at the same time daily life discrimination -associated to HIV/AIDS and to other conditions related to (homo)sexuality and other lifestyles- was terribly obvious. In our study we couldn't verify hostile attitudes towards people living with HIV (for example homosexuals), even when in Argentina, like the rest of the world, those fears were exacerbated in the 80's. Furthermore, we could conclude that the epidemic, with all the pain that it brought, permitted a social learning in terms of acceptance and visibility of differences (Pecheny, 2002).

Theoretical Context

Stigmatization is a way of discriminating. Now, if the verb "to discriminate" is synonymous with "to distinguish" and "to differentiate", it is convenient to describe which forms of discrimination can be consider violations of the human rights. In those terms, we talk about social

discrimination when the State, society, a social group or individual separates, excludes, expels or kills a person or a specific group; when their dignity is attacked and when the exercise of their rights is taken away or denied just because that person or group is different.

Our analysis of HIV/AIDS, and Hepatitis C, regarding the homosexuals' social status and the use of drugs, demonstrates that discrimination isn't a standard phenomenon. We found that discrimination is exercised directly and indirectly. The latter applies when discrimination appears to be a universal rule or action, but it only negatively affects a specific group. We also found distinctions between exercised discrimination, and anticipated discrimination (when an individual anticipates a form of rejection and decides to conceal what ever the motive of discrimination might be).

Among people living with HIV, indirect and anticipated discrimination seem to be more common forms of discrimination than directly and exercised discrimination. But their effects are not less brutal for those affected (Green, 1995). The absence of discrimination doesn't mean that differences should be concealed, or ignored; it is about the recognition of the difference and allowing of its manifestations from the State and the society in general. That is why we emphasize the conceptual difference between social discrimination and social acknowledgement (Habermas, 1985; Pecheny, 2001; Taylor, 1995). Discrimination and acknowledgement have different ways of manifestation depending on the social contexts. In a public/collective level, there is no homogeneity between legislation, public policies, media's point of view, and situations in the workplace, the family, and in peer groups. In a subjective individual level rarely there is coherence between values, discourses and practices. It is very important to asses the different levels in order to get a wide idea on how they work together.

Finally, social discrimination can be analyzed according to political, cognitive, and normative (related to human rights) dimensions. The power dimension is part of discrimination, defined as a specific social subordination relationship. The cognitive dimension exists if there is a distortion or a more or less systematic negative construction of the discriminated group image. The normative dimension intervenes to crystallize and question discrimination relationships. It is necessary to deal with the interaction of these three dimensions in any type of empirical analysis. In that sense, social acknowledgement implies that groups or individuals could increase their relative power, build new images and social recognitions, and modify their legal and normative status at the core of the society. This multiplicity of dimensions is reflected in the stigmatization process, a very particular form of social discrimination. As noted by Goffman (2001b) the stigmatized individual finds him/herself at the center of a territory where arguments and discourses are being debated, mostly about what they should be thinking about themselves and about their own identity.

² Highly Active Anti Retroviral Treatment – it is a combination of two or more medicines to reduce the HIV viral load.

If discrimination is basically a social phenomenon, the actions taken by the victims become part of the public and political sphere even more so. The fact of taking the concealed and stigmatized dimension of the identity to the public sphere, transforms the nature of stigmatization itself.

In the same way as discrimination, the fight for social acknowledgement can be seen at different levels: an individual level, an intermediate social and public level (family, significant others, colleagues...), a general social level, and in a state wide level. Discrimination and social acknowledgement operate at these different levels that determine a set of very diverse individual and social strategies (Pecheny, 2001; Terto, 2004).

Summarizing, the conceptual opposition of discrimination vs. social acknowledgement operates at different levels - depending to the different degrees of "publicity"- and implies political, cognitive and normative dimensions. To assess discrimination and stigmatization should include all these levels and dimensions.

This article focuses upon the experiences of stigma of people living with HIV/AIDS and/or Hepatitis C in Argentina, paying attention to the process of dealing with information regarding their stigma. Our theoretical framework comes from Erving Goffman (2001a) and his distinctions between stigmatized individuals that suppose their difference is well known or obvious to others (the discredited); and those who believe their difference is almost imperceptible to others (the discreditable). In this case the problem is dealing with concealed information that could make the *self* discreditable to others.

This work is about the stigmas that affect people and make them discreditable, and how they overcome the challenges of dealing with the information concerning those stigmas: living with HIV/AIDS, and/or Hepatitis C, the practice or identity of their homosexual sexuality, and/or past and present drug use. The condition of discreditable of this people permits different ways of dealing with information depending on who's who, the context, and time. This "dealing with" is usually very structured, and makes the person's daily life to be out in the open.

It becomes important at this point to ask ourselves: who can be seen as a possible communicator or concealer of these stigmas? What are the coincidences and the differences of each case (HIV and/or Hepatitis C, homosexuality, drug use)? The answer to these questions will help us to examine other types of stigmas. Recent studies have analyzed how HIV stigma is built upon other bigger stigmas like homosexuality or drug use (Kornblit, 2000; Manzelli & Pecheny, 2002; Parker & Aggleton, 2002; Varas Díaz, Serrano García & Toro Alfonso, 2004). In our study we will describe how these combinations of stigmas have repercussions in the "patient role" (diagnoses and treatments), and in their daily lives.

Method

The main objective of this study is to understand the daily lives and the ways people living with HIV/AIDS and/or hepatitis deal with their lives. We used qualitative methodology and the instrument to gather information was the semi-structured interview. Our population was adults from both sexes, HIV positives, positive to HCV (Hepatitis C Virus), or with both infections, that lived in the metropolitan area of Buenos Aires, Argentina. We also interviewed health professionals in the private, social security, and public health services sector, in the same metropolitan area. Interviews were recorded, with the interviewees consent, and a written survey was completed during the interviews (adapted from Pierret, 1998). The interviews were set as a one-time meeting of an approximate length of about an hour and a half. The written survey filled out during the interviews helped us to make a quick analysis of the interviewees' basic socio-demographic characteristics, and it also guided us through the transcription process.

We selected our sample directly not randomly, since our study did not seek statistical representation. The criteria to determine the size of our sample were: relevancy, theoretical purposes, and theoretical saturation (Glaser & Strauss, 1967). The relevancy criteria entails selecting interviewees that could widen the heterogeneity range seeking to find new categories of analysis that could also guide us in the search for new cases. The number of interviewees needed reflected the heterogeneity or homogeneity of the group. The theoretical purpose defined the initial criteria of our intentional sampling which came from previous information gathered from theoretical debates regarding the topic. From that framework we defined each group according to the relevant "theoretical" characteristics of the interviewees. In the case of people living with HIV and/or Hepatitis C, the criteria were: type of infection, mean of infection, gender, and age. In the case of health professionals the criteria were: medical specialty, and health sector they worked at (public or private). We selected a number of interviewees that would allow us to make comparisons between them. The "theoretical saturation" of the sample depended on whether or not we could find anything new about relevant dimensions, and this in turn depended on the complexity of the dimensions that were being analyzed (Glaser & Strauss, 1967).

The sample of people living with HIV and/or HCV consisted of 27 interviewees and the sample of health professionals of 20. Of the people infected with either virus 13 of them were only HIV positive, 5 were only HCV positive, and 9 of them had both. From the interviewees, 8 got the virus from injected drug use, 11 through unprotected heterosexual sex, 7 through unprotected sexual relationships with other men (MSM), and one of the interviewees got infected with HCV from a blood transfusion.

Sixteen of the interviewees were men, with an average age of 34 years. All but one of the interviewees knew of his infection before 1987, the rest got their diagnoses in the 90's although they could have been infected in the previous decade. Some of them had developed different degrees of the illness, while others had not. None of the interviewees were hospitalized at the moment of the interview.

In the health professional's sample of 20 interviews: 8 were infectious diseases specialists, 7 hematologist physicians, 3 nurses, and 2 female pharmacists. From the total sample, 4 worked exclusively in the private sector; the other 16 were from the public sector. Still, most of the interviewees declared to alternate from public to private even when they belonged mainly to the public sector. All of the interviewed nurses (2 male, 1 female) worked in the public sector. Both female pharmacists worked in the public sector.

Our first contact with people living with HIV or/and HCV was through health services, civil organizations (of people living with HIV, gay groups, and former or current IDU), we also used a snowball technique to complete our sample. To initially contact health professionals we went to health centers following leads and suggestions from people living with one or both viruses.

We followed strict ethical considerations in a study with these characteristics (Lee, 1993; Macklin, 2001). Participation was voluntary, and their consent was sought after we explained the objective of the study. Confidentiality was guaranteed for all the information obtained through the interviews. The interviewees were informed about the availability of the information they gave if they wanted to know. At the end of the interview they were given time to ask any question they might have about the interview or if they needed any other information themselves. They were given the contact information of the principal investigator in case they needed to make any further consultations. To analyze the data we used a grounded *theory* approach (Glaser & Strauss, 1967) in order to access the universe of meanings³.

³ In this work we decided to use some concepts of theories that seemed useful at the moment of the analysis of our research problem. However, we must clarify that this study was not designed following only one way of addressing the problem (on the issue of analysis, coding, and interpretation of qualitative data see Strauss, 1987; Dey, 1993; Bryman & Burgess, 1994; Denzin & Lincoln, 1998; and an application in Jones, Manzelli, & Pecheny 2004). In this sense we agree that qualitative research can be seen as a *bricolage* and the researcher as a *bricoleur* (Nelson, Treichler, & Grossberg, 1992). The qualitative researcher as a *bricoleur* conscientiously uses the tools of his methodological work unfolding any available strategy, methods or empirical materials. From this point of view the combination of multiple methods, empirical material, perspectives, and focused observers in a singular theme should be understood as a strategy that adds rigor, broadness, and depth to the researcher's work (Denzin & Lincoln, 1994).

Results

Some of the results related to stigma associated to HIV/AIDS and Hepatitis C, as well as those related to homosexuality and the drug use are presented as follow.

HIV/AIDS and Hepatitis C

If we consider HIV/AIDS and Hepatitis C as individual and collective experiences, with meanings that should be contextualized accordingly to the lifestyles of the subjects (Grimberg, 2002), the moment of diagnosis is very important. A diagnosis implies, from the physician's perspective, a definition of what the illness is, a definition that is embedded in the previous knowledge the patient might or might not possess. In that sense, almost every one of the interviewees had very ample knowledge of what AIDS was, at the moment of their diagnosis. Meanwhile, almost none of them had any knowledge about what Hepatitis C was. Any illness diagnosis allows the possibility to identify it, certify it, and normalize it, establishing certain limits where cure and death are the extreme ends of the horizon. Now, in the cases we are analyzing, not only the horizon is uncertain, but the limits are blurry: neither for AIDS nor chronic Hepatitis C there is a cure, and the "survival" time is undetermined (until recently, a more or less accurate "survival" time was established after an AIDS diagnosis was given out, this was modified with treatment cocktails).

Furthermore, the diagnosis constitutes a milestone, a starting point for a personal situation in which the individual must learn to live with a virus that modern medicine has been unable to eliminate. A diagnosis works like a "before & after" (Pierret, 1998, p. 6). In addition, the ability to analyze the amount of antibodies infected with HIV has allowed physicians to make a specific category diagnosis: seropositive. The moment of the diagnosis is crucial in the biography of individuals affected by HIV, since it does not constitute a mere medical diagnose; it will define also the person's identity. With Hepatitis C, the self identification in relation to the virus is also common, but with two main differences: first, it is less strong than those living with HIV (some people said "such and such is HIV", or "I was not aware I was HIV"); and second, it is true for people that don't have both pathologies, when they are positive to both virus it all becomes part of the HIV/AIDS diagnosis, and Hepatitis C seems not to have any weight at all in determining someone's identity, neither from the point of view of the infected person nor from the people surrounding them.

The people with a positive diagnosis are challenged with whether or not to tell everybody about their test results. Why is this a challenge? First and foremost, because a positive diagnosis implies a series of changes, the reorganization of daily life and, redefinitions of identity and relationships with others, all of this alters life as they knew it. Second, because particularly in the case of AIDS, to our

society and to those affected by it, a positive diagnosis is linked to a series of meanings over-toned with morality, death, homosexuality, promiscuity, and hazardousness. Third, because people living with HIV that do not possess visible marks of the illness, have the capacity of simulation, and concealment that makes them discreditable subjects.

In the case of our interviewees with both infections, they first came to know about their infection with HIV, and then in subsequent tests they found out about their infection with HCV. This has to do with the invisibility of Hepatitis C up until now. Most of our interviewees knew about having the HCV virus when they were already in treatment for HIV. The only interviewee that came to know about both diagnoses at the same time was a woman that went into rehab for drug use. Most of our interviewees were informed about their diagnosis being by themselves; only 4 of them went to get the results with a friend or their significant other. On one hand we have the situation of an HIV diagnosis in which the first reaction is to think about death and in which access to information about the illness and its treatment is an encouragement and a possibility of suggesting a new life project that allows the patients to keep about with their daily normal life. On the other, an Hepatitis C diagnosis first reaction is astonishment, or open ignorance, since accessing information about the virus and its treatment gives a wide identification of the real dimensions of the illness, that leads to despair. These reactions to diagnosis are closely related with the degree of foreseeability of the infection, and with the impact of knowing what a positive diagnosis could have in someone's biography. In terms of access to information, non-governmental organizations (NGO's) seem to be a resource for some gay and IDU on the sample, but not for the rest of the interviewees.

Hepatitis C can represent extreme changes in someone's daily life, but usually it doesn't have visible marks, which allows the person living with it to control the information about it. In comparison to HIV/AIDS, there are no social images related to Hepatitis C. Before knowing of their positive diagnose to HCV, our interviewees didn't know about its existence, or what it implied.

In the cases of people infected with both viruses, HIV/AIDS was paid more attention to and there were more worries about it. Hepatitis C was relegated to a second place. Furthermore, if the patient was in a process of drug detoxification, Hepatitis C could be placed in a third level of importance. At this moment we asked ourselves what were the reasons for this phenomenon? Either it was because of self-experiences in terms of body reactions to the illness, or for the individual or collective perception of the seriousness of the virus or its real pathologies. At the same time we asked, if this could be explained in biomedical terms, and in terms of its symbolical construction.

Back to HIV/AIDS, a good indicator of the wideness and complexity of the dimensions affected by stigmatization represents exactly what happens in the process of

communicating or revealing the serological status of a person. As noted by Varas Diaz et al. (2004, p. 113), if stigmatization wasn't a serious problem, revealing a serological status would be equal to the diagnosis process of any other illnesses to which there are less negative metaphors in society. These authors analyzed the process of communicating the serological status which stands as a crucial moment in which social interaction can be perceived as stigmatizing. As part of the dealing process that implies living with the virus, a very important dimension has to be addressed: how to deal with the information. That is why we asked our interviewees if their "significant other" knew they were living with an HIV positive person, and how they came to know that information. These questions dealing with the notion that family, workplace, faculty, partners or possible partners, among others, constitute crucial contexts in the stigmatization processes.

Regardless of the interviewee's gender, the mother and friends were preferred and trusted with the information of a positive diagnosis to HIV. Fathers, work and faculty companions were mentioned in second place. The situation with partners or significant others was very important. Efficient and/or expected reactions from partners of people living with HIV/AIDS determined not only the quality of life and their mood, but also their propensity to engage in risky or healthy behaviors. In terms of whether or not to trust their partners with their diagnosis information, our study coincided with Green and Sobo (2002) where the nature of the relationship was central to decide this question. Our interviewees trusted their partners with their serological status if they were a stable couple. Sharing this kind of information was not that frequent with occasional sex partners. Some thought it was not convenient to share the fact that they were living with HIV during the first dates or sexual encounters. Meanwhile, others stated it was very important in order to decide whether or not to start a serious relationship. Several of our interviewees said they had sexual relationship usually with other HIV positive persons, which apparently made the sharing of their serological status much easier.

The criteria to share their serological status differed widely among those living with HIV. Different strategies were developed depending with whom they were sharing the information. In terms of their significant other the criteria was: length of the relationship or the amount of sexual encounters, the serological status of the other, the expected reaction from the other, the tests (to prove to the other that it is possible not to get infected), and the type of relationship that had been constructed. All these elements were interconnected, and they might have been, or not, present in all relationships, and have different relevance for each case. Our interviewees accepted there was some kind of secrecy around their serological status, and were conscious

of the strategy of “feeling out” or “sizing up” the other in order to decide whether or not to share their information.

The interviewees stated that one of the reasons not to say what was happening to them was because they thought it was unnecessary (“not to those it is unnecessary for them to know”) or useless (“it has no use for me that they know”), simply because they are not interested in sharing it with others, because they are afraid of being excluded or rejected, and/or to prevent pain to others or to avoid family conflicts. These criteria on whether or not to share information were very well delimited by two motives. In one hand, there was the latent risk of being stigmatized, particularly for homosexuals and IDU’s, since, still today, AIDS represents a powerful social stigma embedded into wider social rejections, like homophobia, or discrimination and branding toward drugs users, specially those who inject themselves. In those terms, many homosexuals and IDU’s perceived themselves as a devalued group inside another devalued group. Besides the stigma of living with HIV or/and Hepatitis C, both groups carried the weight of having to be visualized as responsible or guilty of getting infected by some sectors of society, other people living with HIV, or even by their own family members.

There were other reasons for a person living with HIV not to share his/her information with others. These included: to avoid pity from others, to try to keep daily routines, or to avoid potential discriminatory situations. There was a particular case in which a mother did not tell her son or his school officials, because she knew about other non-infected kids that were discriminated against because their parents were infected. Most mothers living with HIV perceived discrimination against their children as worse than discrimination against themselves. These situations make evident what Goffman underlined before us; there is a tendency to pass on stigma from the stigmatized individual to their closest relationships with others.

There was fear of being discriminated at the workplace because one was living with HIV. This entailed loosing respect at work (“being looked at differently”), having others treat you differently which implies pity, or being the object of jokes or suspicion (of being homosexual and that’s why he got infected with HIV), to simply fear of getting fired. People living with HIV also avoided talking about the matter with people outside their own support network, or that were not familiar with the subject because they believe those people could not be useful at all, and also they did not know what reaction to expect since in most cases they had never talked about it with any of them. In order to decide whom to talk to first about the diagnosis, some mentioned the closest person at the moment (the one that went with them to pick up the results, or the one who waited at home when they got back). It was obvious the need for a buffer zone to handle the impact and the weight of getting a positive

diagnosis, and/or warn people around them in case something happened to them (like getting very sick, or even dying). The also mentioned it to a person from their family (usually the mother), that could have a strategic role in dealing with the information. Generally, a person living with HIV only shared the information of his/her serological status with their most intimate people, or with those who he/she believe were strictly necessary or useful.

In the cases of those infected with both viruses, people tended to focus less on Hepatitis C than on HIV. This was evident for both the patient and people around them. First, for the person infected, the most important information in terms of diagnosis was the one related to HIV, and it was in the reactions to this information where all the fears and expectations were based. Consonant to this, and in second place, people living with HIV perceived that communicating that they were *also* living with HCV was a fact of less importance, because of the relative small space that it occupied in their lives, and also because of its social “insignificancy” in comparison to the charged meanings of AIDS (“a lot of people don’t even know what C means”). Finally, when both diagnoses were communicated at the same time, the emphasis of those listening was on HIV, leaving Hepatitis C at a second place of importance. Those with only a diagnosis of HCV seemed to have less problems sharing the information, although they accepted they concealed the information from their smaller children (just as people living with HIV, or with both viruses). To see the difference between sharing information about being infected by one virus or the other, it is useful to hear Nestor’s testimony (former-IDU, HCV+, HIV-):

“I know that when I start the treatment (for hepatitis) I will have physical symptoms, like bags under my eyes, I wouldn’t be able to be in the same places I was before, in this case it is better for me to tell everyone, if not the fantasy would grow and they will start saying anything like that I am HIV...and between the social burden that would imply that everyone believed I have HIV, and them knowing that I have Hepatitis C, I rather choose the lees harmful, I am still thinking about it.”

What happens after making the decision of sharing the status information, and it is actually communicated? The reaction towards a positive diagnosis was conditioned by the type of relationship between the HIV positive person and the person listening to the information, and the way this information was shared. How these reactions were perceived are key elements in the biography of our interviewees. For them, the positive or negative reactions of their families were more important than the reactions of friends and work companions. After sharing the information, the patient usually received a supportive response from nuclear family members (parents, siblings) and /or it made relationships even better. In contrast, there were some cases in which there was indifference from a family member,

generally when the person living with HIV didn't cleanse their family situation. This is the case when the family knows (generally father and mother) but they "don't get involved", keeping the information silenced, for example.

After sharing the information about HIV with a wide circle of people, some situations associated to discrimination (not getting jobs, close people that left the circle because they didn't know how to deal with the information, difficulties seeing extended family members like nephews, and feeling alone) lead to not wanting to keep sharing the information of them living with HIV to an even larger group of people.

In the specific case of the IDU, when the condition was known (especially HIV) the issue was well discussed. In most cases, they talked about how they got infected, although some family members preferred not to talk about it. In another cases, the HIV diagnosis made the parents to take care of something they knew but were trying to conceal: their son was an injection drug user. This family at first reacted with a lot of reproach for the kind of life he had lived that ended in HIV. Another woman was reproached by her significant other when she communicated her serological status (he got tested and was positive) resulting in separation when she got blamed of infecting him.

Homosexuality

As part of our sample, we interviewed men that had sex with men that identify themselves as homosexuals. In Argentina, like everywhere else, homosexuality constitutes a motive of stigmatization, discrimination, and exclusion. Because homosexuality is not necessarily a visible trait, individuals tend to control the information concerning their sexuality. In a discriminatory context, the capacity to control the information is a way of protection. This source of stigma was not usually shared with the main socialization circle (family, childhood and teenage friends), this is why a teenager discovering his desire towards persons of the same sex won't find support in that immediate circle, and eventually would find rejection from that same circle. In a smaller scale, that interaction lived as a conflict remained throughout the whole life. It was an interaction that is characterized by tension (and relieve) of keeping a secret, or letting everybody know, and to live it more or less publicly (Pecheny, 2003).

Generally, coming out is a selective action. In terms of coming out to their families, the anticipated discrimination (the one that the individual feels can be exposed to) appeared to be stronger than the real or effectively executed discrimination. This anticipated discrimination worked strongly regarding the father figure. None of our interviewees had told their fathers. Other participants said they did not tell their brothers or sisters, with the intention of preventing them, and themselves, of pain and conflict. For the family, knowing a sibling was gay would be a source of pain. To the interviewee, pain would come from rejection after the confession. Furthermore, the interviewees

mention how inappropriate it was to tell them at certain moments, leaving open the possibility to tell them later on. Sometimes, HIV infection played a forced revealing role.

In most of the cases where they came out to their families, the attitude of the nuclear family was of acceptance and communication. This occurred mainly with the mother and siblings; generally the father was not included. In terms of the rest of the family's reaction, our interviewees mentioned acceptance as an attitude, and in the worst cases a "silenced" acceptance of their homosexuality. There was an apparent better acceptance when our interviewees decide to break out the secret of their homosexuality to their family members, instead of them finding out through a third party.

Most of the participants mentioned that all of their friends (gay or not gay) knew about their sexual preference, and that they were the only ones with whom they could talk about homosexuality, even when their friends were not gay. To some, the fact that someone might know about and accept their sexual orientation was fundamental to consider them as friends. When asked about work or school companions, our interviewees shared their sexual preference with a few people using the criteria of closeness and depth in the relationship. Those who knew usually accepted them and talked about it. At the end, "society" or "undetermined others" were perceived as "discriminatory" or "ignorant".

Finally, we should mention that in Argentina also, to fight the AIDS epidemic, the gay community was fundamental in building up material and affective support networks for people living with the virus –including the non-homosexual.

Drug Use

In Argentina there is a strong legislation that forbids the use and possession of a series of drugs, and there is also a high degree of discrimination against those who use them, especially injection drugs. Even among drugs users there is a depictive mark towards those who dare inject themselves with drugs. They are called "pinchetos" (junkies or shooters). In order to avoid rejection or discrimination from their parents, users tend to not talk about drugs with their family; most probably IDU's will distance themselves from their family and develop a stronger bond with their peers with whom they share the same drug use habit. In the majority of our interviews it came across that their family knew about their drug consumption. When the users had children, they knew about their parents past habits (assuming this as a past habit indeed, usually linked to the notion that they had been in treatment). The nuclear family usually rejected the consumption habit with attitudes that ranged from "pissed off" or "worry" to "pain". In any case, they would try to make or force the user to get into some type of rehabilitation treatment.

A very particular group is the so called "consumption friends", that for obvious reasons know about the habit,

will talk about it, accept it and understand it. They are referred to in past tense, and in some cases with a discourse that would not judge them but still describe them in negative terms. This was a way to “avoid” those who were still consuming drugs and distancing themselves from the group, to “change paths”. Some members of this group became an important network of support, especially for rehabilitating drug users and/or people living with HIV and/or Hepatitis C, just because they shared the experience of rejection from others due to their past life of drug consumption and “out of control” behavior. From this group they emerge not only friends, but also potential life partners with a drug consumption past, or HIV. These network of users and former users – just like the networks of gay people – became an important tool to make life easier for people living with HIV: to gain access to support groups, information and more amicable health professional, and to get practical advice. Furthermore, in the drug users case –just like for gays– the personal diagnosis of HIV/AIDS and Hepatitis C – different from the gays– was not a surprise, since all of them had loved ones or member of their close circles that were infected, sick, or had died from either HIV or Hepatitis.

In the workplace generally the information about drug use was not communicated to others, except in work environments related to rehabilitation (addictions counselors, the director of an institution that worked with addicts, and a person that worked in HIV prevention). It was very unusual to share their past as drug users. In a few cases it was shared with just a few close people or a trustworthy person (very similar to homosexuality), although there was not enough information about the criteria to decide to share it or not. In some cases there was a suspicion that their co-workers already knew of their past with drugs.

Finally, there was not enough information or significant patterns that could clarify what happened in terms of sharing information with their significant other. Some of our interviewees had partners while others did not. Some couples shared their habits, or they got to know their partners in the new network of socialization. Sometimes the information was shared with those who appeared in the post addiction time. Sometimes just part of the information was shared (like the fact they injected drugs). An HIV diagnosis could trigger the communication about having been an injection drug user.

People Living with HIV/AIDS and/or Hepatitis C as Patients

A diagnosis and a life with a chronic illness had a great impact in every aspect of the daily lives of people, depending on the type of pathology (Hepatitis C, AIDS) and also depending on the previous or present support networks, usually linked to those same pathologies. Most of our

interviewees mentioned they could count on a family member in terms of who was by their side in moments when they needed to talk about personal things, or when they needed any type of help to deal with the illness. This bond was in constant transformation during the life of the interviewee when dealing with the infection/illness. In some cases, the interviewees could not find support from a close family member. Some participants with a past of drug use mentioned that the infection did not change the dynamics of their families towards them. They recalled their relationship with their family as problematic anyhow. These individuals then tried to find support in friends and professionals. Close friends were identified as very important support networks at the moment of looking for emotional help, in other instances of dealing with the illness, and when they just “need to be listened”. Most of our participants said they were emotionally supported, but in few cases they mentioned receiving any material support.

The stigma that comes along with an illness considered “deadly” or “terminal” carries with it the person’s obliteration of their future, and the inability to foresee long term projects (Davis, 1997). When asked about this, our interviewees stated the following typical experiences. First, projects were perceived as professional/work ventures, mainly about economical stabilization: start/end careers or studies, continue growing as professionals, buy a new apartment, go back to school, and get/keep a job. Particularly, they mentioned the difficulties in terms of the pre-hiring tests – or inversely – to be denied access to public health services if they decide to get a job. Second, suspended projects, or projects that before were considered impossible to achieve, reappeared such as getting and keeping a partner and having children. This last statement surprised us at the beginning of the interviews but we found it was a repeated fact in our following interviews and in other studies about people living with HIV. They felt fine and they explicitly talked about life giving them a “second chance”. This “second chance” was perceived even when they were totally conscious of the risk of prenatal infection, or to pass the virus to their HIV negative girlfriend, as in one of our case studies. Third, and this only refers to HIV/AIDS (not Hepatitis C), homosexuality, and drugs use, some of our interviewees stated that after they received the impact of their diagnosis, they had readjusted their lives, and they even found a way of socio-professional reinsertion in fields related to their pathologies: training and work as operators of self-help telephone lines, as voluntaries, militants, in NGO’s, and in health services. Finally, there were the escaping projects: leaving the country in search of better treatments, and radical changes that would give meaning to their lives. Escaping projects were found in the testimonies of four interviewees.

Health Professionals and People Living with HIV and/or Hepatitis C

When analyzing the role HIV/AIDS and/or Hepatitis C stigma accordingly to the experiences with health professionals working with people living with these infections, we should take into consideration at least two elements: the position of physicians in the stigmatization process, and their role as stigmatizing subjects. The important role of health services professionals has been studied by Goffman: “physicians are the best ones to inform patients of their future situation” (Goffman, 1998, p. 49). Physicians are the first persons to demonstrate to patients how stigmatized they will become to the rest of the society (because of the infection). The diagnosis is usually announced by a physician, and becomes a central social event in the definition of stigma. From this moment on, the individual will become a chronic illness patient, and together with the acquisition of strategies to deal with the infection (regular tests, treatments, dealing with the health system) they will also develop abilities to continue with their daily lives (information control techniques, secret management, and in some cases public/political positioning).

To most of the patients getting to know their diagnosis, the bond between them and their doctor is crucial to understand the social meanings of the infection. In these cases doctors and other health professionals are the only persons with the knowledge about how to deal with stigma. The social learning, with exclusive guidance of the doctor/health professional, will coexist later on with bonds made through out the process with other people living with the illness, with other types of health services (changing the physician), and in some cases with family or friends support networks (depending on how the patient is managing information). This widening of the links that connect the patient with the social meanings of having the infection is part of the very important expertise process, described later.

The health professional interviewed mentioned how patients with HIV and/or Hepatitis C tended to protect themselves through secrecy or by telling half truths. This harmonizes with the slow pace at which information is released. In a lot of cases, patients with both viruses, use Hepatitis C to conceal HIV, as a way of protecting themselves with a disease that it is not as stigmatized by society. Since Hepatitis C has a lesser social weight than HIV, the moment of communicating the infection to family members was simpler. As a result, fewer possibilities of rejection were expected, making the concealment of information less important.

The majority of the interviewed health professionals associated the diffusion of the information with the “quality” of the patients’ social surroundings. From this perspective, it is more probable that the patients shared their information with closer people with who they could open up, people they trusted and from whom did not expect discriminatory attitudes, or because they were experiencing the same

situation themselves: living with one or both viruses. As a result, according to the interviewed health professionals, the majority of the patients first told their significant other, who in most cases was also living with one or both viruses. They shared this information if they were a steady couple, if they felt they could trust them about what was happening in their lives. At the same time their significant others were the only ones the doctors pressured the patient to tell for reasons of risk of contagion. Meanwhile, in terms of revealing the diagnosis to anybody else, our interviewees thought it was a patient’s personal choice, since it was part of their private lives.

Many times, fear of discrimination lead the patients to not reveal their infection to anybody, fearing they might be excluded, or even fearing losing their jobs. Not revealing this information to other significant social relations made the physician and health professionals the only ones they talked about the infection (sharing this exclusivity with the media and any other information about the virus they can find by themselves). This entailed a very restricted social learning about the meanings of the infection in our society. In the other hand, to reveal the information can get the patient access to a series of social interactions that we had described.

As health professionals and specialists in the treatment of these illnesses, they become part of the social space (in a more or less organized way) of people living with the infections. They become part of the patient’s social surroundings as empathic figures (people that know “how it feels”) (Goffman, 1994). In many cases, this empathic figure role leaves the scene at the moment of closing the health center, but in many other cases their insertion in the social space of people living with these illnesses is framed in their “commitment with the cause”, getting involved not only with the clinical treatments, but also with the life conditions and sustainability of their patients. In some occasions, and in extremes cases, this commitment can make health professionals assume the “representation” of the patients. In any case, the insertion of these professionals from a general medical field, occurs after their participation in the social space configured by people living with the illness, so to speak, they embodied another social space configured by specialist in HIV and/or HCV, and then the rest of the paraphernalia it involves (congresses, journals, publications, researches, clinical essays, travels, economical profit, professional links).

A second element to consider when analyzing the role of stigma associated to these illnesses among health professionals is their role as stigmatizing subjects. In our study, we found that few health professionals and health center employees had direct stigmatizing attitudes towards those living with one or both viruses. The stigmatization process was built, as we pointed out before, over other social stigmas like those regarding behavior practices that

were consider risky (IDU's), sexual identities (gays, transgenders), and lifestyles. Previous studies in Argentina (Grimberg, 2002; Kornblit, Giménez, Méndes Diz, Petracci, & Vujosevich, 1997) have also found that the construction of HIV/AIDS from a biomedical perspective in the health system has created stigmatizing categories, linked to groups and practices perceived as "risky" (homo/bisexuality, drugs use, sex work) categories that would appear as responsible of the emergence and diffusion of the illness. This marks the appearance of a scale of values in which drugs users—especially injection drug users—were the most stigmatized by the health system, followed by transgenders, and men who have sex with men. This leaves heterosexual patients that do not use drugs and that might got infected with HIV or Hepatitis C by sexual contact or by a blood transfusion at the other extreme of the scale. This is the testimony of a female infectious diseases physician:

"Drugs addicts are like the worst in the health system... I am telling you what doctors say: "Dude, the junkie is yours, you see him". Who's next? Transgenders come next in the scale, generally they come in group, they make noise... they revolutionize the waiting room because they are treated in the men's ward but they are girls... girls that want to be treated in the women's ward. It is a festival dance over there, a brothel.... Then you come up in the scale if you're gay."

Interviewer: -"There is also rejection towards gays?"
"Yes"

Interviewer: -"So, we can say that it is ideal to be heterosexual and not use drugs to go get health services?"

"That's the way they teach you at medicine school, the faculty is very conservative."

It was interesting to make synchronic analysis on each and every one of the interviews and to find how some health professionals can detect discriminatory attitudes in other professionals, not realizing their own discourses are also contaminated with the same attitudes.

Analyzing the testimonies from health professionals and health center employees, we found differences in treatment and conception of the patients living with HIV/AIDS and those only infected with Hepatitis C. Our interviewees didn't talk that much about Hepatitis C, giving priority to comments related to HIV/AIDS. This silence is evidence of a double invisibility, first they don't talk about the C virus, and secondly they don't realize they don't talk about it. In other words, there is a double movement by which the importance of a chronic illness (of increasing epidemiology relevance like Hepatitis C) is denied in the biomedical environment. When asked about HIV/AIDS—an illness they are constantly talking about—some health professionals manifested that even when it was true that patients were treated better than before, there was greater discrimination and prejudice against them than against people living only with Hepatitis C.

In terms of secrecy and/or publicity of issues as patient's homosexuality and drug use, most of the participants demonstrated being uncomfortable and said that these issues were part of the patient's private life which regularly came up at the physician interview, but generally was not addressed directly. This may cause problems because the fact that a patient is gay might be related to specific diseases, so if the physician does not know about the patient's sexual activities he would not be able to prevent or to early diagnosis these diseases. Drug users could have a similar situation because if the primary physician ignores these practices there could be inconveniences for Hepatitis C patients.

In terms of the stigma related to other individual characteristics, we found that most of the interviewees perceived IDU's as difficult patients, aggressive, and causing trouble for health professionals. Some stated that they need help treating these patients so they could deal exclusively with the clinical issues and they understood that the patient's drug use presented other challenges. Drug users were seen as "bad patients" that do not adhere to treatment and cannot commit to a long term treatment. The patient's disobedience was perceived as a challenge to their authority. This negative perception was presented by the participants regarding their colleagues and themselves. They showed a desire to help patients quit drug use but the generalized attitude was rejection of drug users and a profound ignorance about people who engage in these practices.

For health professionals these patients had difficulties adhering to the treatment regimen which made them fail the treatment making more obscure their future perspectives (Pecheny, 2004). However, analyzing the interviews of participants living in drug abuse situations we found self-care strategies and care for others, which made possible their adherence to treatment. The interviews also presented a clear difference between types of drug used.

There were not definitive positions of rejection towards homosexuals as there were for drug users. It was clear that the politically correct discourse was not to discriminate against homosexuals, so none of the participants openly acknowledged rejection for this population. Even though most stated that they did not felt rejection among other professionals, a considerable group did identify rejection from colleagues. Contrary to the perception of IDU's, homosexual patients were perceived as good patients, complying with treatment, responsible, and with a positive attitude towards the fact of living with the disease. This demonstrates that complying with treatment norms is a key element in the construction of good and bad patients; norms that are not established by the patients and that reflect the authority of professionals.

Homosexuality, as long as it was not explicit, did not bother physicians who could talk to their patients in a neutral way without directly addressing the issue. Some female

physicians recognized that beyond the argument of the private life of the patient, it was culturally difficult to address issues of sexuality, harder if it was prohibited. In this situation instead of addressing sexual practices, physicians talked in general terms about issues of transmission focusing exclusively on medical terms and prevention, excluding a social point of view.

Health professionals also had a negative view of transgenders. Professionals considered them to be conflictive patients, not only because of their behavior, but because of their sexual identity. When the “information” about their sexuality cannot be disguised, as in the case of transgenders, a tense situation at the physician’s office and treatment centers was developed and professionals did not know how to react. The physician calls a patient for treatment with a male name and a female figure appears. Issues related to how to address these patients and where to place them for hospital treatment presented difficulties for health professionals. This situation confused them and made them react by making jokes and openly discriminating transgenders. It is important to state that even with this differentiation between homosexuals and transgenders, discrimination and stigmatization still persisted towards both groups among health professionals, regularly disguised by the need to show a politically correct attitude towards these populations. Transgenders appeared to be the highest group exposed to mocking which underlines the strong rejection against them that still exists in society.

In summary, by analyzing the role of stigma related to HIV/AIDS and/or Hepatitis C, as presented by health professionals treating people living with this conditions, we must take in consideration their role in the stigmatization process as their role as stigmatizing subjects. Health professionals in general presented a low predisposition to stigmatize their patients in basis of their disease, however stigma shifted to other behaviors, personal characteristics or life styles. This influenced the quality of care, and particularly patient’s human rights.

Patients as Experts

Patient-doctor relation influences the “patient capital”. This capital of information and autonomy is greater among those that come from or integrate themselves to social networks of people directly or indirectly affected by the disease, for example networks of gay people, former drug users or current users, and people living with the disease. The “expertization” of people living with a chronic disease is a phenomenon that we feel important to highlight. By this term we designate the process by which these patients acquire a determined level of knowledge, specifically in medical terms, that separates them from lay people; bringing them near to those with the legitimate knowledge in the matter, the professionals. This body of knowledge can be discursive (it can be express in words) or practical (the know-how).

As the field of the body of knowledge in HIV/AIDS and Hepatitis C is not homogenous and does not have all the answers, the knowledge of the patients becomes a legitimate

competitor with the state of the art knowledge. It is also possible to analyze up to what point the context of medical “not-knowing” and “no-power” delineated a type of patient-doctor relation characterized by asymmetry and less distance than traditionally attributed to this relation.

Being an expert basically implies an increase of knowledge of the disease by the one who suffers it. As we said, the people that we interviewed initially had some HIV/AIDS knowledge, more or less precise, more or less correct, at the same time that almost none knew what Hepatitis C was or its implications, generally confusing it with “common” Hepatitis A or B. This lack of knowledge changed immediately at the moment of diagnosis and knowledge increased through months and years of living with the disease. Knowing about the etiology and transmission modes allowed the person to formulate hypothesis on how and when they got the infection. Some people expressed knowing exactly how it was, others had a somewhat correct hypothesis, and some did not know because they could not identify in their life history any risky situation (particularly in Hepatitis C).

In the personal discourses of these people the issue of “how” was not presented with high concern at the moment of the interview maybe due to the time passed, their fatalism or as not to add guilt to an already difficult situation. By contrast, almost all participants expressed feeling that others did present them with questions about “how”, which made social interaction difficult based on the stigmatizing supposition that there were “innocent victims” and people who “looked for it”.

In the cases which occupies us here, the subjective way of living the disease in loneliness determined the relations with significant others and in different social spaces. In this sense the interviews showed the existence of a positive or negative feedback between the subjective living with the disease and the social link with others. In this way the normalization of the subjective impact goes hand and hand with the level of trust towards close people or, to the contrary, with “new” or unrelated people. They did this following a trial and error process: you develop trust in yourself, trust others; you evaluate how it was and this positively or negatively feedback the process. Most participants expressed having had fear in trusting information about their disease to others at the same time that they did not find rejecting attitudes, but some indifference, from family, friends, and colleagues.

The learning developed by these people about these diseases included several aspects related to symptoms, treatment, medication, medical terminology, clinical tests, reactions from others including health professionals, and developing the ability to access places or specialized professionals. Learning to read the signs provided by the body is one of the fundamental issues in these patients’ trajectory. Learning to correctly read the signs and to act in

consequence is particularly critical for people living with HIV and Hepatitis C because of their undefined asymptomatic period and rollercoaster evolution of the infection. In both cases there are expected and feared signs that could predict serious complications and eventually rush decision making for the beginning or change of treatment modalities. Reading laboratory reports was one of the indispensable knowledge that patients acquired with time, which validated or rectified their corporal experience. The knowledge of treatments and regimens included information on medical terms, risk and side effects, and the technical ability to follow the treatment. Some participants that used to be drug users expressed their ability for drug injection applied to the use of injected treatment. At the same time others expressed that using injections for treatment reminded them of their previous cocaine use.

The knowledge on medications was related to the quality, its effects, counter indications, ingestion procedures, prices, and ways of acquiring them without having to pay. The use of medical terms was incorporated to their daily language, including among people or family who are generally outside the scope of the subject. Sometimes medical terms were reformulated and included in daily life, not always with fidelity to its medical origin or by ways of elliptic figures. For example, Susana (38 years, low income, HIV/HCV+) said:

“I have been undetectable for two years, I have 777 CD4... Cannot transmit the bug by sexual relations, I could transmit it by blood but not through sexual relations.”

Evidently, the undetected are her antibodies or virus, not herself.

As we can see, an important issue is the anticipation of others' reactions, related to discrimination or support, including health professionals. Anticipation allowed determining to whom and how to trust the information about their infection or their children's. This knowledge was crucial and doubt and uncertainty constituted one of the major agents of anguish for people affected. For example, this happened to mothers of children in kindergarten or at a summer camp. In the same manner, people try their surroundings with the objective of knowing who will be of support. This trial and error provided valuable information that reduced uncertainty because “someone who suffers a chronic disease that ‘waits too much’ or ‘makes too much demands’ probably will be more rejected by others. This means that the person who is sick must continuously evaluate the possibility of expressing their demand to others” (Nettleton, 1995, p. 69). Subjects become experts in knowing people, environments, and more or less amicable relations in respect to their health condition which is crucial for the success of their treatment and for keeping their quality of life.

The ability to get access to treatment and medications is another essential knowledge to increase their quality of life. Studies on daily life of chronic patients show a trait found in our interviews in terms of the variable of time: the longer the

time living with the infection, less fear of developing the disease, less fear of near and inexorable death, and less uncertainty (Pierret 1998, p. 66).

It is interesting to note the relation between becoming an expert and the existence of networks of people living with the disease or peer networks (e.g. gay men, drugs users) at the same time that we examine the role of the non-governmental organizations (NGO). In this sense, we found mostly through the testimonies of gay men and some former drug users, that NOG's and self-help groups had an important role in their process of becoming experts and learning to live with the disease. This process was mostly identified from the initial diagnosis up to the normalization of their infection several months later. Becoming an expert was more evident in families with multiple people with the disease. We found several of these cases, for example one female participant mentioned that her partner, sister, brother in law, one of her children, and her brother's mother in law, all lived with HIV/AIDS or HIV/AIDS and Hepatitis C. Other cases showed partners living with the same disease either simultaneously or not.

Discussion

The participants established a hierarchy of motives for stigma in their rejection scale. Among former drug users what is most rejected was their previous drug use, secondly the fact of living with HIV/AIDS, and finally the Hepatitis C diagnosis. HIV was sometime perceived as a simple consequence of drug use and sometimes could be seen as positive in terms that HIV make them ‘reach the bottom’ and abandon another disease, drug addiction. In several cases Hepatitis C infection was seen as a lesser evil compared to HIV, as perceived by those with the co-infection or those only with Hepatitis because of the feeling of ‘escaping the HIV even if they have been injecting’. The perspective of having HIV was different for gay men for whom homosexuality was not something to reject or regret. They acknowledged the stigma but did not blame themselves. For this reason, in their rejection scale the first (and probable, the only one) place was occupied by HIV.

Social and family discrimination due to AIDS, real or anticipated, had a notable effectiveness: the perception or fear of rejection from their social and emotional environment acted as a self-exclusion factor. The situation was more difficult when the revelation of serostatus came with the revelation of non-public behaviors, particularly homosexuality or drug use. In this line, several testimonies presented the fear of reactions due to lack of information (“they don't understand”, “they discriminate”, “they hurt you”, “its shocking”, etc.) and, in particular fear of discrimination from their personal environment (specially family) and “other undetermined” people for which the individual cared for (“the society”).

Through out this paper we traced similarities, differences, and articulations in terms of the management of the

information on homosexual identity, being drug users, and living with HIV/AIDS and Hepatitis C. We analyzed these issues as non-evident traits of discreditable individuals, which allowed a relative concealment and fears of revealing their secrets. So much as these issues were motives for stigma; discreditable individuals would want to carefully conceal them from determinate people. “Even in the case that someone could keep a secret, a concealed stigma will reveal that social relations ratified in our society by mutual confession of concealed defects, will make them to reveal their situation to their close friends or to feel guilty if they don’t” (Goffman, 2001a, p. 92). In our analysis the increments and the differentiated strategies, context and time, taking in consideration that the person who hides will pay attention to social situations that others assume without much care or special calculations (Goffman 2001a). Many of the different reactions between the communications of both issues come from the obvious differences that separate a sexual identity from a disease, although both may act as motives for stigma and are socially perceived as related.

Now, in terms of personal trajectories people living with HIV/AIDS usually changed from anger and fear, to fighting against the disease. This feeling of “being in charge” of their own lives generally implied a change in social network participation; change that provided for other personal ties in terms of management of the information about sexual orientation and living with HIV. This was so at least in two senses, first letting others know about their HIV infection status could contribute to revealing a more or less discreet life of homosexuality – revelation that would imply a redefinition of ties with others non-homosexuals, which could reaffirm friendships and family bonds or separate them. Second, for many homosexuals their HIV diagnosis led them to finally define their gay identity and to develop strong ties with peers and others living with HIV/AIDS.

The AIDS epidemic produced a forced ‘coming out of the closet’ for many homosexuals whose sexuality was protected by the limits of their intimate space. This individual phenomenon became a social issue because homosexuality since the AIDS epidemic became an everyday topic in the media and governmental instances. Paradoxically, the AIDS experience accelerated the inclusion of the subject of discrimination and the human rights of sexual minorities in the public scene, allowing a redefinition of the subordinate status of homosexuality as a stigmatized practice relegated to the private sphere of discretion.

However, this optimistic panorama with regards to occidental societies has its limits for many of our participants who had not modified their criteria for revelation of their information even after knowing their HIV diagnosis. Some fears (from family’s failure to understand, to loss of employment capability) made them conceal their serologic status or their sexual identity. The origin of these fears is precisely the fact that the perception of society is that homosexuality and HIV/AIDS are mechanically linked.

Family, friends, labor, and sexual/affective relations of people living with HIV/AIDS were conditioned on a daily

basis by this control on the information (or secret) in a profoundly homophobic society, which rejects drug use and discriminates against HIV. As reminded by Gabroe (VIH+/HCV+):

“If there are people that I don’t want by any means to know that I have HIV...? This is complicated, because many times I proposed myself to keep anonymous so it does not... it does not harm me that others know... because of the fear of discrimination, but it is stronger than me... and sometimes it comes out, you see. Because I... I am not ashamed that people know, really it does not bother me, if it bothers others it is their problem...”

As Goffman (2001a) states, if something from the past or present of the individual is discreditable, his precarious position seems to vary directly with the amount of people that are involved in the secret. As more know about the obscure side, more treacherous the situation will be (p. 96). The tension of the secret as a constitutive element of interpersonal relations acted as a life condition of the participants in our study. We tried here to elaborate only some of the consequences associated with such a tension in daily life in the expectations of other studies that could address and critically examine the tension of secret as a life condition for people living with HIV/AIDS.

This analysis makes us reflect on the different forms of the experience of the disease: in each individual and in the relation of each individual with his/her vision of the social image of their disease. In terms of AIDS, as more accepting is the individual vision (from himself or from what he perceives from society), the closer the HIV/AIDS experience comes to that of Hepatitis C, to the banality of daily live, and the authorization for future vital projects including having children. Inversely, the graver the perception of Hepatitis C, that is, the less it is associated to Hepatitis A, the stronger the vision of living with an infection becomes, and the experiences of uncertainty will be similar to those related to HIV/AIDS.

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