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2.7 *Social representations of the hiv-aids complex amongst Spanish gypsies*

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The Spanish Gipsy Community

When we talk about the Gipsy community, we are referring to a large group – the number of Spanish Gypsies varies significantly according to the different authors, ranging from between 800,000 people to over 1,000,000 – that doubtless forms the oldest and first historically recognized ethnic minority in Spain. In order to understand and explain why Spanish Gypsies today occupy a culturally, economically and politically subordinate position in the Spanish state, the contextual references, in historical, political and economic terms cannot be avoided. This subordinate position, in turn, conditions their perceptions and practices regarding health and illness, as well as HIV-AIDS, as will be seen throughout the present article (*).

The first historical references to Gypsies go back to the 15th century, the time at which information is recorded about the arrival of small groups of nomad Gypsies to our country, as also occurred in other European countries. The writings which analyze this historical period and successive ones (SÁNCHEZ ORTEGA M.H. 1986, SAN ROMAN T. 1986) explain in a precise manner the different ways in which the Spanish dominant culture has situated the Gipsy minority on the outskirts of main society (1). In these works it can be observed, throughout five centuries of Spanish Gypsies and Payos (2) living together, how a whole set of conflictive relationships developed, marked by a deep inequality between the majority and the ethnic minority. Although summarizing large historical periods in a few lines inevitably implies a large degree of simplification, it can be said that Spanish Gypsies have been submitted to two contradictory tendencies during their presence in this country, tendencies which both have in common the incapacity of the main society to understand the importance of their integration as full-right citizens, without this necessarily implying their assimilation. These two tendencies can be observed on the political level through the different

polities that the Spanish monarchs dictated concerning the Gypsies (SÁNCHEZ ORTEGA M.H. 1986).

On the one hand, during the periods of expansion of the Spanish economy, the integration of the Gypsies is firmly asked for, as long as they abandon the distinctive elements of their identity, which are not only cultural (dress, language) but also constitute their most traditional ways of life (nomadism, specific professional activities). During these periods, it can be glimpsed how the State attempts to constitute not only a controllable citizenship (which explains the insistence that they abandon their nomadic way of life), but also a culturally homogeneous one. In those times many Gypsies did integrate, although the stereotype was already firmly established, and in spite of many laws that favored their settlement, for example in rural areas, they met strong opposition on behalf of the Payos. It must be underlined that in these integration movements Gypsies were only allowed to occupy the lowest positions in the social scale. Nevertheless, during these periods many Gypsies fully incorporated the mainstream social life, although in most cases by finding specific economic niches; they were situated in the social margins, but were allowed a certain autonomy and control over their survival.

On the other hand, during the periods of economic depression, the Gypsies were expulsed out of these margins, which were occupied by the lowest social class of the Payo society (SAN ROMÁN T. 1986); their level of survival fell, and it became necessary for them to search for new niches in the social margins. The great impact that the industrialization processes in Spain exerted on the Gypsies must also be highlighted, since they led to the disappearance of practically all their traditional trades. Due to all this, it can be sustained that the Gipsy group is a subordinate one, submitted in a dominant way to the hegemonic society, which owns the capacity to situate it through its own history and according to its own processes of development; in this case, ethnicity is the criterion which defines the subaltern position. Through these processes, and like any subordinate group, the Spanish Gipsy community developed specific resistance mechanisms, which although they did not lead to a change in their position inside the network of unequal relationships, at least enabled them to survive for 500 years, with more or less good fortune. I believe that some of the most defining characteristics of the Gipsy culture – family relationships, speed, intra-family solidarity, sharpness, etc. – are part of this resistance culture.

At the present time, the Spanish Gipsy community is characterized by its almost total sedentarism, by its internal diversity (geographical but mainly in terms of social structure), and for maintaining some of the traits that

best served it, through the centuries, for its social reproduction. Among them, the kinship organization – based on patrilineal lineages, territorially dispersed and spatially organized in big family groups, a great importance being given to matrimonial alliances that increase the power of the lineages[3] – has played and is still playing an essential role as a survival mechanism. It is this large kinship group, living together in a close geographical area, which, from my point of view, constitutes a sort of Gipsy "survival mattress". It represents an important point of support in difficult circumstances and can be mobilized for help when one of its members is in a hard situation. This aspect is particularly relevant, as shall be seen hereafter, when health and illness problems are at stake. The organization around age and gender, as principles which articulate positions of authority and "respect", also make up the characteristics of "being Gipsy", without, of course, constituting an exclusive trait of this group. In particular, the marked androcentrism of the Gipsy gender relationships is not so distant from the androcentrism that prevails in the Payo gender relationships.

In nearly all investigations about Spanish Gypsies, the necessity to recall that this community shows, at the present time, a great internal differentiation is underlined. In our investigation work, we found that the vectors which best describe this intra-ethnic diversity are differentiation by social stratum, and by geographical area (Castilian Gypsies, Andalusian, Galician Gypsies, etc.), with the difference that when we talk about the Gipsy community, the social strata cannot be compared to those that exist in the Payo community. What we call Gipsy high class (these persons, still few in number, who in the last generation have had access to university studies, because their parents' generation had been able to obtain a stable employment paid according to Payo standards) would correspond to the Payo middle class, and so on for the other classes. This means that when we are talking about Gypsies it is necessary to go down one level in the general social stratification, this situation being the result, as I have mentioned, of the unequal historical relationships between the majority and the Gipsy minority. The Gipsy middle and low classes – to which the great majority of Gipsy families belong – are separated by a very thin line, which is easily crossed because of the economic ups and downs I have previously mentioned. Families, which in a situation of economic stability have a medium level of living with professional activities such as sales in markets, work in construction, or agricultural labor, may rapidly fall into the deepest marginality in a moment of general economic recession. Equally, it is in these moments that family support and help mechanisms are activated, as well as a possible professional diversification of the group. To this regard, and

although it is not the object of the present article, it is interesting to point out that the traditional social stratification by classes is made more complex when it meets the existence of unequal ethnical differences, as in the case studied here.

As for the geographical setting of Gypsies, it is important for two aspects. The first one has to do with the auto-identification of subgroups that the Gypsies themselves establish, these sub-groups being endowed with specific characteristics of an identitary type (Andalusian Gypsies are..., Castilians do not...), which in most cases refer to behaviors considered as distant or close to the ideal "being Gipsy". And the second aspect is directly related to the higher or lower possibility of integration of the Gypsies into the main society, and thus to a stronger or weaker stigmatization process. For instance, it is easier to be an Andalusian Gipsy than a Galician Gipsy, since some defining elements of the Andalusian culture are permeated with Gipsy elements. When analyzing an identitarian process, dialectical relationships between majority and minority cultures have to be taken into account. Hence, considering that a geographically defined Gipsy sub-group possesses more Gipsy characteristics (meaning a higher observance of Gipsy traditions, and thus a higher conservatism), we must take into consideration the fact that possibly the Payo society with which the group is living also presents a higher conservatism. For example, it is not only that Castilian Gypsies are more conservative, but also that the Castilian society is more conservative in general.

Social and health conditions

We do not have much bibliography at our disposal about the specific health problems that affect the Spanish Gipsy population, although there are writings that inform us about living conditions of the majority of Gypsies[4]. The theoretical perspective adopted in this investigation connects health and illness problems to the historically constituted forms of social reproduction. In other words, this perspective characterizes health-illness-care processes as fundamentally *social* ones, as it considers that inequalities and differences in health aspects cannot be explained in a detailed way without relating them to the social inequalities and differences built up through long historical processes. This vision is quite distant from the dominant biomedical perspective, which by linking illness to a momentary situation in a personal life, prevents from showing the coherence, links and continuities between the subject who suffers an illness as a social subject and the

social surrounding, and thus a pathogenic evolution that, beyond the solely personal dimension, may be understood as a social one. The case studied here is very pertinent, since the Gipsy ethnic minority has suffered such a long process of social exclusion, and there is no doubt that the analysis of health and illness processes in this community may present a high explanatory capacity that reflects social inequalities.

It is therefore not surprising – as it is indicated in some writings – that the Gipsy population should have a lower life expectancy that the Payo one, and not only in absolute terms, but also in relative terms by social stratum; or that the ageing process should be more premature in the Gipsy population, and the vital time sequence should be adapted to this fact, so that consequently Gipsy ages are defined by other parameters than the *Payo* ones – a Gipsy is adult at 18 and old at 45. Nor is it surprising that, given the living conditions in shantytowns – where a great number of Gypsies have lived and are still living – infectious diseases should be a daily problem. These facts are the mere result of exclusion and marginalisation, and therefore need, in order to be eradicated, something more than changes in the individual health behaviors and practices, although these are also necessary in many cases. The data presented here tends to show that illness, in the Gipsy case, owes much of its specificity to the condition of poorness that accompanies most Gypsies throughout their lives, which therefore implies that a "radical prevention" [5] would require the elimination of the poorness and inequality of conditions in which the daily life of an important sector of the Gipsy community takes place. It has been pointed out very often that the strife for decent housing – for Gypsies, although not only for them – and for a job that may enable integration, without assimilation, is a question of personal and collective dignity. I want to add, furthermore, that it is a question of health.

HIV-AIDS and the Gipsy community

It is useful at this step to indicate briefly why a research study on Gypsies and HIV-AIDS was undertaken. In the first place, and taking into account the strong connotation of AIDS as a disease laden with symbolic meaning and social prejudice against its carriers [6], it is necessary to recall that *AIDS is not a Gipsy disease, although some Gypsies are infected by this virus*. The epidemiological pattern of AIDS among the Gipsy population follows the same parameters as in the Payo population: the great majority of persons were infected through the sharing of needles in the context of parenteral drug

use. This Spanish epidemiological pattern is quite different from the ones that prevail in other occidental and African countries.

Therefore, as some Gypsies fell into drug use, especially those in a situation of strong marginality and social exclusion, and shared needles in their drug use practices, they were affected by the AIDS virus, and much more in the past years than at present. Indeed, as shall be seen thereafter, the large number of deaths and the harm reduction programs reduced little by little the impact of AIDS through this contagion route, among Gypsies as well as among Payos. The main objective of our research, launched at the request of *Secretariado General Gitano*, was to obtain a knowledge of the representations that the Gipsy community holds about AIDS and to explain them, and also to find out if certain characteristics of the Gipsy community could help, or on the contrary could impede, an adequate prevention regarding this disease. It is therefore a theoretical project, but one which also implies a practical engagemet towards a better prevention of AIDS in Spain [7].

Representations of the HIV-AIDS complex

As E. Menéndez and T. Seppilli, among others, have shown in many occasions, health-disease-care processes constitute consistent – but not closed – complexes, which articulate knowledge, representations and practices that enable social subjects and/or groups to face and fight suffering. In this way, specific conceptions about the etiology of a disease conform certain practices concerning care and treatment. These practices are consistent, although not exclusive, in the sense that several medical systems can be activated in order to explain a disease as well as for attention and treatment, according to the opportunities and/or possibilities available for the person, as a social subject, to get access to knowledge and to institutional or non institutional systems of prevention and treatment.

From this point of view, my interest was mainly to understand, and if possible to explain, the common and different aspects of the Spanish Gypsies' knowledge of the HIV-AIDS complex, constantly considering that this knowledge has to be related to the images and projections about HIV-AIDS that developed in the *Payo* society, since the social formulation of HIV-AIDS stems from the majority's hegemony and especially from that of the bio-medical sector.

The problem is therefore to explain, on one hand, the intra-ethnic variations and constancies, and on the other hand their links with the general representations of HIV-AIDS [8].

Definitions of HIV-AIDS

Definitions of HIV-AIDS can be grouped in three descriptive forms, which constitute three main conceptions of the complex that are rather quite different.

In the first definition, we find a medicalized discourse, and a concrete reference is made to a disease underlined as *infectious and contagious*, transmitted by a *virus*. Mention is made of *antibodies*, different *phases* are distinguished, the *difference between being sero-positive – having antibodies – and having declared AIDS* is known, and references are made *to the existence or non existence of defenses, as well as to the idea of opportunistic diseases in the declared AIDS syndrome*. The following sentences could summarize this conception:

> "Well, AIDS goes by phases, the first, second, third and fourth or terminal phase. When I found out, it was already too late (her husband who died of AIDS) was practically already in the fourth, terminal phase. You can have the virus in your blood. When you catch the virus, you have it, and then the different phases develop, and you can catch certain infectious diseases. This is when you're already in the disease's phases, because if you've only got the virus they can give you a treatment and this can check it. Then when the bug spreads, this doesn't mean you're going to die, because if you don't catch any infection you don't die. I don't think anybody really dies of AIDS, it's because of the infections that it brings, in the lungs, tuberculosis, in the kidneys. AIDS infects you but you can still live with a person who is a carrier of AIDS, and if you treat him on time it can be stopped. I know of a case in ..., who since this person was going to pass away, you can't imagine how many died in the meanwhile, and this person is well, in the fourth phase. This person doesn't smoke, nor drink, nor use drugs, and is on Retrovir... Cancer is death although it's not contagious. AIDS is more dangerous because you can pass it on to people, but you die before with cancer. Cancer is more efficient for death" (Middle-class woman, husband died of AIDS).
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> "HIV, well to my daughter they could have changed her blood and she would have been a normal kid, a healthy girl. But when she was four they found out she had positive antigens, that's AIDS already. With AIDS you catch other diseases, for example my daughter has funguses in the mouth or in the gullet, they call them candidiasis. It grows into your mouth and prevents you from eating, or swallowing, but this all comes from AIDS. AIDS can be solved if you live a normal life and take your medicine. Within a few years it will be like any chronic disease. The doctors told me, it's going to be like as if you had a chronic hepatitis or chronic asthma. It'll be like any other disease." (Low-class woman, sero-positive, infected by drug using husband, daughter with AIDS).
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> "Well I've had antibodies for 16 years, I'm sero-positive and my level of defenses is 651, my viral charge is undetectable. At the beginning I thought that antibodies and AIDS were the same thing. I mean, you said "AIDS" and you were going to die. Now I know that the antibodies are there, they're blocked and I've been like this for 16 years. The antibodies, I'm in the A2

> stage. Sero-positive persons are sero-positive, but in the terminal phase you have A, B, C, and then A1, 2, 3, 4 and the same for B. But in the C4 phase there's no... it's the worse, the terminal phase, maybe you've got two days left or a week at the most. I'm in the A2 stage, although my pancreas is bad." (Low-class man, sero-positive, ex drug user).

As can be deduced from the previous statements, in this conception not only the bio-medical definition of the disease has been assumed in a rather precise manner, but also it's development, the distinction between being sero-positive and AIDS, the existence of opportunistic diseases related to AIDS, and which are those that kill, the possibility of a normalized life with others, the existence of antiretroviral treatments that turn the infection chronic, and the necessity to maintain healthy practices in everyday life. The image of AIDS as death is thus broken. But above all, HIV-AIDS is considered an infectious disease, for which attention and care is required, as in practically any other disease. And mainly, all types of social metaphors are avoided.

The persons who have this type of conception, of which the previous discourses are examples that appear recurrently, present the following characteristics. In the case of women, and independent of the social strata they belong to, the terminological precision regarding the infection is determined by their role as direct caretakers. Even in the case of the sero-positive woman, all the statements about HIV-AIDS are made concerning her daughter's disease. This example is very significant, because in her relationship with AIDS the woman refers to herself solely as her daughter's caretaker, and only talks about her personal situation (being sero-positive) to underline that she can't think too much about it nor worry too much because this would prevent her from taking good care of her child.

In the case of women, therefore, whether they belong to the middle or to the low class, it is the personalized care of a person with AIDS – as a wife, a mother, an aunt, or a sister – which determines the important competence they acquire regarding knowledge about the disease. This situation seems logical, if we consider on the other hand that as caretakers, they are the ones that have had most direct contacts with the doctors who attended or are attending their family members. In this case, the possible lack of economic and/or cultural capital is compensated for by the specialization that their social role leads to (social capital).

In the case of men the situation is somewhat different. The specialization in medical language stems from the personal and individualized experience of the disease. It is when they find out they are AIDS carriers or patients that they acquire knowledge about the infection. But it must be un-

derlined, as it will be shown later, that in most cases, men, moreover, mention the loss of prestige and the social consequences of being an HIV carrier. For the infected male Gipsy, the disease, although it is described in medical terms, is very directly related to its social consequences. The centrality of the man in an androcentric system explains on one hand the possibility of feeling that one is the individual subject of the disease, which thus needs care (that others will provide), phenomenon that does not occur with women. And on the other hand it also explains that the man should feel he is the main subject affected by the social consequences associated with the disease – for instance he shall not easily establish contacts for matrimonial alliances for his sons and/or daughters, or in case he's a bachelor, he will not be able to get married. This situation is one that favors the *concealment* of the disease, in the case of sero-positive men.

The second main conception of HIV-AIDS still considers it as an infectious and contagious disease, but the specialized knowledge is blurred and some metaphors begin to appear when describing it. The term virus is not used but is replaced by the word *bug*, the different phases of the disease are not distinguished unless in a metaphoric way, and a popular discourse, related to the theory of internal consumption and of germs, is superimposed upon the medicalized narrative about AIDS. This can be observed in the following statements:

> "AIDS is a bug... for instance you have the bug, you inject first..., and then the one that injects after you catches AIDS ... or antibodies... or the virus or whatever it may be. You know this is *death*. You know it's *something that's going to kill you* little by little, with time it's going to eat you up." (Low-class man, closeness to AIDS through sero-positive prison mates).

> "The thing is that the bug *eats you up* little by little... you have it inside your body and gradually it consumes your blood until time passes... and if you don't take your medicine you die quick." (Low-class man, brother died of AIDS).

> "They say *he has something bad, or the bug, he has the bug*. But you don't call this disease AIDS. It's the bug that gets inside and starts eating you up from inside... that's how they told us in the class we took... and those who already have the bug, well they end up like skeletons. I saw it in a movie... it's sad to see them." (Middle-class woman, no nearness to HIV-AIDS).

In this conception, the association of AIDS with death is clearer; it is something that will come sooner or later, and can only be delayed. The skeleton and the internal consumption metaphors are very important. The logic established between the cause (the bug) and its action is very obvious: if you have a bug inside, this bug eats you up from inside and the result becomes visible on the outside. Among men, it must be underlined how

they put an emphasis on the slowness of the process, as an element of cruelty added to the consumption process. In this conception, no difference is established between sero-positivity and AIDS. It is all part of an undetermined set, although there are still some references to a pathogenic agent, the bug. AIDS is considered as a disease where the bug enters from outside, contrary to others for which a bug is also mentioned – mainly cancer. You ask for it, and hence you could avoid it. The blaming of the subject for having certain behaviors is implicit in this conception. But nevertheless there is still place for a certain distinction concerning the routes of contagion: by injection, by sexual intercourse.

Those who sustain this type of conception are: middle and low class women with infected distant family members and/or neighbors, who thus have never been thrust in the situation of the direct caretaker, but still have references of not too distant personal contacts; or women whose knowledge about HIV-AIDS comes from attending short classes where they were told about the disease, or from the information they got from the media, that exert an impact that must be taken into consideration. In these cases, it can be seen that although a more official and medicalized language is used – "they told us", "they said", "we saw a movie" – this language is adapted and mixed with terms that are closer to their own socio-cultural conceptions. In many cases these terms are associated with the germ theory – the word germ is sometimes used instead of virus or bug – and this is important because of its link with ideas concerning forms of contagion and preventive measures necessary to avoid infection.

Low and middle class men who are in a situation of direct closeness with infected persons – close family members, cell mates – but who themselves are not infected, are those who hold this type of conception most often. This situation would correspond to that of the care-taking women in the first category, but in this case, and due to the differences in social roles – they are not direct caretakers – and although they may have very close relationships that are affected, their discourse is an intermediate one between popular socio-cultural forms and bio-medical knowledge. In the case of these men, closeness gives a more precise shade to knowledge but does not generate a true specialized one. In the same way, among women, routes of contagion and preventive measures are tied in a conception marked by the idea of diffuse contagion – by air, through the mouth, by injection, through sexual intercourse but without specifying more details, etc. – in which medically proved routes of contagion for HIV-AIDS are mixed with other ideas that belong to popular culture, and not only to the Gipsy one. We must keep in mind that *in this conception, as well as in the other two, and*

given the androcentric orientation of the Gipsy culture, men of all socio-economic strata only consider themselves as subjects who can be infected and never as possible contaminating subjects. And this is very important because it constitutes the basis of the prevention measures they take, especially regarding sexual relationships: they may use a condom in sexual intercourse with unknown women, so as not to be infected, but do not use it with their own wife because they are sure they will not be infected by her.

The third main conception of HIV-AIDS is one that directly relates the disease to social aspects. In this conception, the characteristics of the disease as infectious and contagious are diluted, and all the language refers to social relationships, to risk groups, and finally to everything that condensates evil, in terms of social evil. Knowledge is articulated by attitudes of moral valuation of the disease and the discourse is built on total and absolute externality: AIDS is the disease of others, of "bad" others, not as sick persons but as representatives of a "bad life". This is how it is told:

> "Wow, how scary! This is the worse there is. People know, I mean, if you catch this you die, it's the *drug addicts'* disease, druggies have it because they shoot up, of course, they shoot up and they catch AIDS". (Middle class woman, no contact with HIV-AIDS or drugs).
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> "Then there was this other case of a boy who died of AIDS also, and you know, people knew, because this boy was a drug addict, his father is too, *they're not well accepted*, and the brother's also a drug addict and now he has AIDS, and the wife also, she's on drugs, *she's Payo*'. (Middle class woman, no contact with HIV-AIDS, brother with past contact with drugs and now in the cult).
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> "AIDS is like a *punishment for doing what shouldn't be done*. It isn't spoken; nobody talks about it. It's what happens to drug addicts, I think, or to people who've been with a drug addict. What I do know is that it can't be cured. I don't have anything, I'm touching wood, thank God". (Middle class woman, no contact with HIV-AIDS).
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> "Here, among us, it spread very little, I don't know, it's as if it doesn't exist among us. *AIDS among Gypsies sounds weird, it sounds ugly, it sounds like.. how should I put it? Disgusting, it's a bit strong to say a thing like that*. It sounds bad – when the interviewer asks for a comparison with cancer – both are bad, because both mean death, but cancer would be better than AIDS ... from cancer you also die but there's not contagion, which is a *shame*. It's a shame because it means you've been on drugs or with women. But *cancer* is a *disease*, and it just comes because it comes. I prefer dying from cancer than from AIDS" (Middle class man, bachelor, distance from HIV- AIDS and drugs).
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> "The diseases that worry me most are cancer and AIDS, because you die and because they affect more people. I'm personally more worried about AIDS than about cancer, it frightens me more, because it destroys you in an *uglier way*, if you catch it it's not because of... it's because of *bad things, like drugs, or,*

> *well, sex too*. I think it has more to do with people who go to *funny* places." (Middle class man, bachelor, distance from HIV-AIDS and drugs).
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> "Yes, people are frightened about AIDS, but the thing is that since *we're not druggies* and nor do we... this disease, the people that have it are *homosexuals*, and since we don't have them here, it's something that's not going to affect us. I'm not a druggie, my kids aren't druggies, and we're not fags either, then this disease isn't going to affect us". (Middle class man, married, distance from HIV-AIDS and drugs).

Persons with this third type of conception are mainly middle class men and women, with a marked distance from actual cases of HIV-AIDS, and also distant from cases of drug use; hence they reproduce the most socialized discourse on AIDS: the one that was built with the first medical accounts, in which it was related to specific risk groups, drug users, homosexuals, and promiscuous persons, and which at the time normalized HIV-AIDS by linking the disease with socially rejected groups. In this sense it represents the discourse of normality – of Gipsy as much as Payo normality. This conception enables them to make a moral valuation of other people's life; those who move around weird places, who have a different sexual life, and especially those who are blemished by a thing like drugs. Slight differences are not admitted for these men and women, and it is not actual subjects they consider guilty, but whole sub-groups. Routes of contagion are those that have to do with life styles that are morally valuated as negative. Because of this, it is a dangerous conception, since it prevents making risk practices visible in a non-moral way. The pathogenic agent of HIV-AIDS is "bad life", which is always other people's life: druggies, bums, fags. We are often told that AIDS is a "punishment", which implies that it is just, as a "purgatory" for a "bad life". This is why, for people with this conception, images of surprise appear when cases of sero-positive or AIDS-affected persons' wives are mentioned: they are innocent and unexplainable victims.

This conception is held, as in the case of the Payo majority, by social groups that are in a position of dominant centrality within the Gipsy group. It therefore bathes the images of all sub-groups. It isn't spoken of it bringing "shame", because it is related to social evil, to the most condemnable forms of life from the viewpoint of social normality. Thus when it is talked about, it serves to express fear in a rhetorical way, although the subject rapidly moves this fear aside by affirming that he himself cannot get infected. Since AIDS is built upon externality with regards to oneself or to one's near relations, it reaffirms one's own moral quality. It enables one to draw a line between oneself and other non-normalized forms of life. But because this sub-group is the one that builds Gipsy normality, it is in this

case that AIDS is most often linked to Payo life. It is the same discourse as the one held by the majority society, except that it works the other way around. If in one case the correlation Gipsy / drugs / AIDS is established, in the other case the correlation is Payo /moral degradation: homosexuals, prostitutes / AIDS. Unfortunately, this stereotyped conception, on both sides, is the one that dominates and that we should try to change, underlying once more that HIV-AIDS is only an infectious and contagious disease.

Among the mediators, the elite, and the Payo professionals who work with Gypsies, an interesting situation arises, which shows their liminal position between two worlds. They know the main aspects of the HIV-AIDS complex, this knowledge being acquired through the training they received, through their own economic, social or cultural capital, or through specialized professional knowledge. In all of these three cases, the most medicalized discourse on AIDS is efficiently used. Nevertheless, afterwards, Gypsies are talked of as others, distant and strange. They are all attributed the most socialized conception on AIDS, the third conception: "they don't talk, they don't know, they hide it", without trying to understand the differences and the internal logics of the variations. They reproduce, in a certain way, the stereotype of main society. But mostly, and more important, they incorporate in their own conception some images of this third set of representations about HIV-AIDS in a non conscious manner, and in this sense they end up associating traditional Gipsy prevention practices – all the set of practices concerned with avoiding infectious and contagious diseases – with forms of ignorance and lack of knowledge, and therefore spend much of their efforts in trying to destroy them.

Finally, many Gipsy men and women indicate the existence of suburban ghettos as the main cause of the group's lack of protection in the face of diseases and AIDS, establishing a direct link between forms of social reproduction of inequalities with health and disease processes in general, and with HIV-AIDS in particular. From this Gipsy viewpoint, which is also our theoretical and methodological starting point, the emphasis is set upon structural conditions as the main risk factor for HIV-AIDS. It is underlined that these structural conditions foreshadow and conform certain life styles in which individual practices acquire their meaning, and therefore cannot be studied separately. If we consider the development of the HIV-AIDS pandemia in the world from a historical perspective, with its conversion into a chronic disease and a clear epidemiological decrease in occidental countries, when at the same time it shows a brutal increase with a very high

probability of death in poor countries, we can only conclude, as many Gipsy women and men indicate, that *poverty and pauperization constitute one of the main contagion agents of HIV-AIDS*. This last point of view agrees with the *emic* and the *etic* perspectives.

Conclusion

Although the Gipsy community has these different representations about the main routes of HIV-AIDS contagion, its members apply a whole series of preventive measures, when they are close to an infected person or an AIDS patient, that refer to the existence of the idea of diffuse contagion, related to the popular practices aimed at avoiding infections by germs. Indeed, in presence of an AIDS patient, the near kin uses all the prevention practices that are part of the popular and scientific culture regarding infectious and contagious diseases, which is in fact the characteristic of some of the opportunistic diseases of AIDS. When the ill member of the family lives in the home, the objects he uses for eating and for hygiene are set apart, and cleaned separately; moreover, visits are avoided, especially of children, and when the patient is already in a phase of declared AIDS. The patients do not consider these measures as humiliating, and in many cases they themselves apply these measures so as to protect their family. On the contrary, the loss of respect and social position brought about by the knowledge that someone has AIDS is underlined by Gipsy men as the main source of suffering. Social isolation is directly related to the domination of the most socialized conception of HIV-AIDS, in which contagion is associated with socially "reprobated" forms of life, and which imposes a set of practices that, instead of being really efficient in terms of prevention, constitute moral practices of conformation of a determined normality in which AIDS patients cannot be integrated.

This paper has had as its goal to show the variety within the gipsy Spanish community, and in conjunction with this, the several representations of one complex problem like the HIV-AIDS inside this community, all of which try to break the most common stereotypes about the uniqueness of the "gipsy world".

Notes

(*) The material presented here is the result of a research led by a team of investigators formed by Rosario Otegui, Amelia Sáiz, Arancha Meñaca, F. García Selgas and Antonio A. García. This research was made possible thanks to the support of the Fundación para la Investigación del Sida en España (FIPSE), which financed the field work carried out during the year 2001.

(1) For those who are discovering the Gipsy world, the historical works by M. Helena SÁNCHEZ ORTEGA (1977, 1986) are absolutely essential; this author reconstituted very carefully and in a most detailed manner the complexity of inter-ethnic relationships in Spain and the different periods where it can systematically be observed how the government polities have situated the Gypsies in social exclusion, even in the cases where shy openings enabled brief periods of integration. A. GÓMEZ ALFARO (1999) also provides interesting documentation about the advantages and drawbacks of the deportations to America in the 18th century. On the other hand, Teresa SAN ROMÁN (1976, 1986, 1990, 1994) is without any doubt the social scientist that has best studied Spanish Gypsies, allying in her works the details of ethnographic descriptions with a theoretic reflection about the complexity of inter-ethnic relationships that are bathed in inequality, as in the case referred to here. In her different works, which cover more than twenty years of Spanish Gipsy history, it can be observed how the changes in the main society have enabled, or on the contrary hindered, the integration of Gypsies as full-right citizens. Nevertheless, as she explains, the second class citizenship granted to the Gypsies has only permitted, in most cases, the Gipsy people to "adopt, or be forced to adopt in all places marginal solutions that are fundamentally "*liquenistas*" (parasitical)" (1986, p. 206).

(2) "Payo" is the term used by Gypsies to designate members of the non-Gipsy population. It is a usual term among Gypsies, but conveys a certain depreciative tinge, when used by a Gipsy. This is why, some times during my field work, and especially with Gypsies from Castilla León, I also found the term "paisano" (compatriot) used for non-Gypsies. For reasons of language economy, and knowing that the term "Gipsy" also has a certain pejorative connotation when used among non-Gypsies, I will make use of the two terms: "Payo" for members of the Spanish non-Gipsy majority and "Gipsy" for members of the ethnic minority.

(3) For more details see SAN ROMÁN T. (1976) and following, GAY AND BLASCO P. (1999), GAMELLA J. F. (1996), ARDEVOL E. (1986).

(4) GIEMS (1976), GAMELLA J. F. (1996), SAN ROMÁN T. (1986), MONTES J. (1986), CEBRIÁN (1992), FRESNO G. (1993) .

(5) I am using the term in the same sense as MENÉNDEZ E. L. (1998).

(6) For larger information concerning the different ways in which Social Anthropologists have investigated AIDS and the over-stigmatization processes that are implied when associating AIDS with certain social groups, see R. OTEGUI (2003) (to be published).

(7) This project will end after a second phase of field work, in which I shall collect specific information about what it means to live with AIDS in the Gipsy community. I must indicate that although this was not the main objective of the first part of the research, a certain number of our informants were HIV carriers. The ethnographic material was collected in Madrid, Valencia, Galicia, Andalusia, Navarra and Castilla León.

(8) In order to explain the heterogeneity regarding ideas about AIDS, the three variables that we found were most significant were: closeness/distance to HIV-AIDS, gender, and socio-economic stratum. The precision must be made that a distinction is established between what we name general social construction of HIV-AIDS, in which images and concepts are associated with the historically constituted forms of general discourse about HIV-AIDS – for example with reference to "risk groups" –, and what we call the medical construction of the disease, in which bio-medical terms are used and controlled for its description. This does not imply that I am not conscious of the important role played by the bio-medical discourse in the social construction of AIDS. In this sense, and although the present investigation is concerned with the Gipsy group, it must be underlined once more that *Gypsies, when they use the social construction of HIV-AIDS, do it in a manner very similar to that of Payo majority members of equal characteristics*, as will be shown in more detail hereafter.

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