

Prometheus bound. Immigration and HIV infection.

by Laura Spizzichino*

The sailors could already see the most secret recesses of the Bridge and the impervious peaks of the Causasian mountains stood out, where Prometheus, his limbs attached to a sheer wall by unbreakable bronze chains, was having his liver eaten by an eagle that incessantly dove down upon him.
Apollonio Rodio, *Le Argonautiche* (III secolo a.C.)

A monkey and a fish were surprised by a terrible flood and risked being dragged away by the force of the water laden with flotsam. The monkey saw a tree branch within reach and he pulled it towards him, saving himself from the foaming waters. Then, wanting to help his friend the fish, he went back into the water, picked him up and put him on the branch too.
The moral of the story is: Good intentions are not everything. If you want to help the fish, you need to know its nature.
Ancient Chinese fable

It is best to be very cautious in thinking about immigration and HIV infection. There is in fact the risk of forming an idea of a close connection between the two issues. It is true that mobile populations can be particularly vulnerable to the risk of contagion due to a series of factors, namely: origin in a country of high endemic occurrence; social exclusion, language and cultural barriers, difficulty in accessing health services and being reached by preventive campaigns. Not to mention the possibility of being involved in the traffic of human beings and/or prostitution. To get a real picture of the situation one has to rely on epidemiological data from the Sistema di Sorveglianza delle nuove diagnosi [Surveillance System of new diagnoses] (Suligoi, Boros, Camoni & Lepore, 2009) of which only some Italian Regions and Provinces are currently part. Between 1992 and 2007 in these areas the records showed about 23 thousand new infections, 22,4% of which were in foreign citizens. The percentage per year increased from 11.0% in 1992 to 32,8% in 2007. These increases however can be attributed mainly to the progressive growth in the number of foreigners present in our country rather than a real increase of HIV in the migrant population. In fact, if one examines the incidence, that is, the number of new diagnoses among foreigners in a certain period compared to the number of foreigners present in the same period, it is clear that, compared to the increase over time of the annual number of immigrants newly diagnosed with the infection, the incidence is falling because their numbers in Italy have considerably increased in recent times. Therefore from 138.5 cases per 100,000 male foreigners and 75.8 per 100,000 females in 1992, the numbers fell to 64 and 52,4 respectively in 2007. These levels are however still high if compared to those of Italians: 7 times higher in 1992 and 11 times higher in 2007.

In a context of this kind, we need to think about the psychological needs of foreigners with HIV and about the psychotherapeutic interventions to put in place in order to respond to them.

Today, as we know, a diagnosis of HIV infection is no longer a death sentence as it was in the early years of the epidemic. Thanks to the introduction and spread in developed countries of the new pharmacological treatments which have proved to be more and more successful, there is a considerable reduction in mobility and mortality among HIV-positive individuals and in the transformation of the infection into a chronic illness. This however does not mean that at the same time all the problems of those who have to live with the disease have been solved. In fact, precisely because it is a chronic illness, it requires

* Psychotherapist, senior psychologist at the Risk Behavior and Infective Diseases Operative Unit at the 'ASL Roma E', Rome, Italy. Communications to: lauraspizzichino@gmail.com.

periodic tests and a pharmacological treatment designed over the long term and, as a result, a series of adaptive tasks that the patient may find it difficult to deal with and which may give rise to considerable stress and psychological disorders of varying degrees of seriousness. The critical points that are generally dealt with in the clinical psychology intervention with migrants affected by HIV can be compared to those of Italians. They are (Spizzichino, 2008):

- accepting the new condition and making adjustments to coexist with the virus, with all that this involves;
- revealing one's HIV-positive state to significant others;
- adopting safe behaviors as regards oneself and others;
- accepting the therapy and complying with it.

However, in the interventions for foreigners, the possible interference of cultural peculiarities must be taken into account, as well as the conditions the immigrants live in. There are in fact some specific culturally-mediated aspects that can influence the understanding and perception of HIV infection and consequently the individual vulnerability towards the infection. Among these we can mention:

- the different interpretations of medicine, sickness, sexuality, death, shame, propriety, reputation;
- the difference between male and female roles;
- cultural beliefs about AIDS.

Regarding this last point, in the case of people from third world countries where there is no access to treatments, we can mention the image of HIV infection as an illness with no hope, that always causes pain and death. This involves a dissonance with the messages about the chronic, controllable pathology that it has become today. Or there may be the persistence of the idea that certain blood groups or certain people are immune to the virus, or that God protects some individuals rather than others.

The perception of risk, too, is closely linked to the culture one belongs to. For example, for Ethiopian immigrants, AIDS is closely correlated to poverty: since Italy is a rich country, they think there they are not at risk and therefore do not take precautions (Martini, Di Pasquale, Cohen & Pizzirani, 2004). Roumanian men, brought up under the Ceausescu regime, when people were forbidden to talk about contraception and prophylactics, are far more unwilling to adopt effective preventive practices.

Moreover, every ethnic group has norms and conventions that govern the expression of pain, the description of symptoms, the way of communicating pain and symptoms, beliefs about the causes of illness, an attitude towards those who help you, expectations about the modalities and outcomes of treatment. All this may have important effects on the motivation to seek treatment, on the coping style, on how supportive the family and the community will be, on the kind of person to turn to for help (psychologist, family doctor, priest, healer), on the path to take to find a treatment, on the prognosis and on the outcome.

"In our culture we aren't used to going to the psychologist: we prefer to keep things to ourselves"
A., 19-year-old Roumanian woman¹

Managing to adapt to life with HIV is linked to some personal and environmental variables such as:

- the patient's personality traits;

¹ The passages in inverted commas are taken from counselling and psychotherapy sessions. Some of them are quotes from Spizzichino (2008). *Counselling e psicoterapia nell'infezione da HIV. Dall'intervento preventivo al sostegno psicologico*. Roma: FrancoAngeli.

- the patient's sociocultural characteristics;
- the presence of adequate social support, especially the presence of affectively significant people;
- the characteristics of the health facility and the staff's ability to establish a relationship of empathy, understanding and control.

Adapting, in any case, is not a stable achievement because HIV infection is intrinsically evolving: think, in fact, of the stress of clinical and laboratory tests to monitor the progression, of the appearance of new symptomatology, and of the need to start pharmacological treatment.

"You don't accept the illness, you live with it, but you never really accept it. I don't believe people who say they've accepted it. Some days you get so depressed, if you get a problem, a cold, you immediately think of the virus".

B., 20-year-old HIV-positive male

"Now I manage to get the thought of HIV out of my mind, not like at first when it was always the fixed thought in my mind. It's like having a black hole next to you: if I look down into it I feel sick, but I ignore it, I look ahead and keep walking".

C., HIV-positive for the past 2 years

"I wouldn't have imagined that only a year after the diagnosis I could feel like I do today. Paradoxically, after I fell ill I learnt to appreciate what I've got, especially my family. I've reached an equilibrium that I don't think I've ever had".

D., 50.

It can be said that the whole existence of HIV-positive individuals is marked by a thin red line representing uncertainty. It may be tied to the decision to take the test, to wondering who could have given them the infection, to the possibility that they may have infected others, to the best time to start the therapy, to how effective this will be and for how long, to the long-term safety of the new drugs, of side-effects and developing resistance.

In the case of foreigners, the experience of uncertainty connected to the illness can weigh heavily on and worsen the state of uncertainty typical of an immigrant's life, above all if he is an illegal resident. Moreover, the secrecy about being HIV-positive, a crucial point which people with HIV have to face for fear of stigma and discrimination, is worsened for the immigrant by the fear that the news may spread in his community and reach his family in his homeland. This can lead to a state of isolation with serious repercussions on psychological wellbeing, but may also mean that the patient does not comply faithfully with the doctor's prescription for fear of being discovered taking the medication.

"I feel the secrecy is a weight, I feel as if I should be ashamed of having this illness".

E., 30-year-old South American man

Living with the infection, even before the beginning of the pharmacological treatment and later during this treatment, therefore involves periodic tests to assess the clinical situation and the progression of the illness. This means having continuous contact and a relationship with the infectivologists and any other specialists of the health facility. In the case of immigrants, taking it for granted that the current access to health care continues even for illegal immigrants, then clear, detailed instructions need to be given at the time of diagnosis.

"The doctor told me the diagnosis using difficult words and technical terms without making sure I had fully understood. I had the idea that it was something serious but I understood it was HIV only when I went to the hospital for the therapy. I am still very confused".

F., 27-year-old South American woman

But above all, what is essential is to think about the health services themselves, about the way they work, about any barriers present for people belonging to other cultures, taking into account the needs of these people, and the representation they have of the health services and their staff.

A further aim of the psychological intervention with people with HIV is *empowerment* and assertiveness in interacting with the medical team in order to obtain a good control of their health. A central role in this should obviously be played by the infectivologist who should provide the patient with the necessary information, suited to his level of knowledge, explaining the options available and putting the patient in a position to actively participate in the various decisions. In fact, a patient personally involved in the decision-making process concerning the pharmacological therapy is more motivated to correctly follow prescriptions (Roberts, 2002; Malcolm, Ng, Rosen & Stone, 2003). But the attitude of the patient, too, is decisive in creating the conditions to become active and involved in every aspect of his own health.

“At first I didn’t understand anything and didn’t ask any questions. I listened to the doctor who, without many details, said it was going as it should and confirmed the therapy. If I asked questions or expressed fear for example about the future side effects of the drugs, he cut me short saying that the side effects were nothing compared to what the illness could cause if it wasn’t treated. Every time I left feeling confused and frightened. Then I learnt that I had to assert myself, that I had to politely insist on explanations, and I didn’t leave until I had cleared up the doubts and fears that came up from one visit to the next and were discussed during the psychotherapy sessions. The change in me caused a change in my doctor who became less hurried and more willing to talk to me”.

G., 45-year-old South American woman.

The disclosure of the fact that one is HIV-positive to significant others is an issue loaded with problems that creates anxiety second only, according to the literature and to patients’ testimony, to receiving the diagnosis. The perception of this important step is often influenced by the fear of being abandoned, discriminated and isolated, or of upsetting family members, above all of making them feel ashamed, and duty-bound to help. Moreover, for some there is an added difficulty, since it may mean the revelation of sexual choices until then kept secret or carried on illicitly, of drug-use or of extra-conjugal relations.

For those who belong to other cultures, the disclosure is tinged with further problematic nuances and there is the additional fear of breaking family bonds, losing economic support or suffering from physical violence. In some societies, in fact, women are often blamed for the infection of husbands even though they were infected by the men themselves, and they can be expelled from the house and deprived of any economic or social support (Gielen, O’Campo, Faden & Eke, 1997; Temmerman, Ndinya-Achola, Ambani, Piot & Temmerman, 1995).

It must however be stressed that provided the disclosure of one’s HIV-positive status is not done impulsively, but dealt with in due time as one of the steps in a decision-making process including the analysis of each stage of the dilemmas, barriers and decisions (Serovich, 2000), it has positive repercussions on the life of people affected by HIV. According to the WHO (World Health Organization, 2004), those who have made the disclosure have found greater support and acceptance, closer bonds with family and friends, and a lower level of anxiety and symptoms of depression. In contrast to the patients’ expectations, it has also been shown that the news is not necessarily associated to a breakdown of stable relationships underway.

“We had been married for 10 years when, after a serious illness, we discovered that he was HIV-positive. I didn’t think of leaving him even for a moment. We went on together, initially both shocked, then gradually calmer. I was amazed at myself: I was a rock”.

H., woman aged 40.

The clinical psychology intervention with people with HIV must also deal with the issue of at-risk behaviors both for the patient and for others, focusing on the aspect of altruism and concern about one's partners' wellbeing, but also on that of their health and therefore on the need to avoid superinfections with resistance to drugs and other sexually transmitted infections.

In past years, preventive interventions were especially oriented towards training HIV-negative individuals to adopt behaviors that would prevent them from being infected; the message was that each should protect himself. But in the light of the latest data on the state of the epidemic, from all sides comes the pressing call to address the HIV-positive population (Centers for Disease Control and Prevention, 2003) as soon as possible after the diagnosis (Colfax et al., 2002).

An aspect that tends not to be taken seriously enough is that of the efforts that people with HIV need to make to avoid infecting others. Although it may seem obvious that they have the responsibility not to spread the virus, not enough attention is given to the psychological difficulties they encounter in making changes in their habits and above all in maintaining them over time. In any case, the attention must be placed on choosing strategies that appeal to people's sense of responsibility without creating guilt feelings or encouraging or reinforcing the social stigma.

In general, it has been found that the aim can be achieved if individuals are considered in their complexity and not only in the aspects of sex and substance use. Other issues that need to be dealt with specifically are relationships, work, health care, as well as the stigma and discrimination suffered.

In this area, too, work with immigrants involves some difficulties connected both to their conditions and to the culture they come from. An undeniable fact is that it is difficult to reach them with informational and educational campaigns about safe behavior. The perception of sickness and risk also play a crucial role, as we have already said. Lastly, it is necessary to think about the deep motivations, often culturally mediated, that drive people to take risks and about the intrapsychic needs that this serves to satisfy. At any rate, changing towards safer behaviors is a process, not a final destination, which takes time and needs to be supported and reinforced because relapses are the rule, not the exception.

The pharmacological therapy is a central aspect of working with people affected by HIV. The new therapeutic protocols, available since 1996, are proving to be highly successful, granting longer survival and a better quality of life. For this to happen, however, at least in view of our knowledge today, it is indispensable for individuals to know they are HIV-positive, to access the healthcare services, to take medication all their life, with no interruptions of any kind, to show strict adherence to the pharmacological treatment. It has been estimated that, in order to obtain an optimal virological and immunological response and avoid opportunistic illnesses, the adherence must be at least 95% (Paterson, Swindells & Mohr, 2000), a level that is certainly very difficult to maintain over time. However, more recent research (Nachega et al., 2007), that examines regimes based on newer drugs and has observed more than 2800 HIV-positive adults for over two years, suggests, in confirmation of previous studies on smaller samples, that it is already possible to achieve viral suppression if the adherence is 50% and above.

If we think about the situation of the immigrants in this area, what emerges first is a worrying fact: late diagnosis. This is a phenomenon widespread in all the rich countries: in Italy, according to the surveillance data (Suligoj et al., 2009), the proportion of patients with a diagnosis of HIV-positive less than six months before that of AIDS increased between 1996 and 2008 from 20,5% to 59,7% and it is highest among those who contracted the infection through sexual relations with foreigners. Among the latter, in particular, the delay concerns 70,9% of the total number of immigrants as opposed to 38,4% of Italians. Obviously this has important consequences in terms both of the spread of the virus and of the pharmacological treatment which if started early, is more effective.

In our country the drugs against HIV and the related tests are free for all, including illegal immigrants. It is therefore extremely important for them to learn of their HIV-positive condition in Italy where the state of the infection can be checked and therapy can be

obtained. As we have said, in fact, in some countries, especially African but also Asian and European countries, this opportunity either does not exist or is very limited. In December 2006, in sub-Saharan Africa only 28% of those who needed therapy were receiving it, although this is certainly a great step forward compared to the 2% of three years earlier. In the same period, the percentage of HIV-positive individuals under treatment was 19% in Asia and 14% in Eastern European countries where resources are at a low to medium level. Certainly the most penalised are children: only 8% of those who should be receiving therapy have access to it and only one pregnant HIV-positive woman out of ten is given prophylaxis to reduce the transmission of the virus to the infant² (World Health Organization/UNAIDS/UNICEF, 2007). This is due to various factors (Giuliano & Vella, 2007), namely:

- the cost of drugs;
- possible conflicts with other health emergencies;
- lack of adequate health infrastructures;
- lack of training and updating for health staff;
- complexity of antiretroviral treatment;
- the problem of stigma and discrimination.

So while on the one hand receiving a diagnosis of HIV infection in a rich country gives the opportunity to be treated,

"It's a godsend having discovered it in Italy, otherwise I could never have got treatment. I can't help thinking of people with the same disease that have stayed in my country and can't do anything except wait to die".

I., aged 30, born in a sub-Saharan African country.

On the other, foreigners are indissolubly tied to their host country in cases where antiretroviral treatment would be precluded in their home country.

"I have started the therapy, I feel well, but I can never go back to my own country. There are no medicines there, I'd die. I won't see my family anymore and they won't be able to understand why or if they find a reason it will be unjust towards me".

L., 27, South American

For these patients therefore we could talk about a Prometheus syndrome, from the name of the titan that Zeus ordered to be chained to the highest peak in Caucasia. It is marked by a sense of being uprooted, the experience of loss, isolation, loss of confidence in the future despite the expectations of survival, anxiety, sadness and depression. They feel chained down, being unable to return to their home country because their life-saving treatment cannot be interrupted. This is all the more true for immigrants 'without papers' who have no way of re-entering Italy after a brief stay in their home country. Continuing with the myth metaphor, the reference to Prometheus takes on a further meaning since he was placed in that painful situation without hope - Zeus swore that he would never be set free – as a punishment for giving fire back to men. And the idea of punishment often recurs in clinical work with people affected by HIV, both Italians and foreigners, who feel that the illness is God's punishment for "bad" conduct, for their past risky and irresponsible behaviors.

² The chance that the child of a woman with HIV will contract the infection can be greatly reduced with the application of a protocol that envisages the administration of antiretroviral drugs to the mother for the entire duration of the pregnancy and during childbirth, and to the child for the first month. It is also necessary to carry out a Caesarean section before labour starts, and not to feed with breast-milk. In this way the risk falls from 25% to 0-1% depending on the studies.

A delicate phase for those with HIV is when pharmacological therapy appears on the horizon. This is often experienced as a sign that the situation is getting worse and the end is near. In actual fact, the international guidelines tend to bring the times further and further forward, and the treatment therefore takes on a preventive role, in the sense that it starts when the organism is still healthy and therefore able to respond better and to tolerate any side-effects from the drugs. This is obviously if one is not forced to intervene in an emergency situation in the presence of serious pathologies or even in the AIDS phase, due to a late diagnosis.

The clinical psychology intervention must therefore deal with this aspect, setting itself the further aim of responding to the need for information about the issue that many HIV-positive patients, especially foreigners, reveal.

Some of them, especially straight after the diagnosis, are impatient to begin the pharmacological therapy.

“The number of CD4+ is high, the viral load³ very low. The doctor said that for the time being I don't have to start the therapy. This makes me unhappy, I'm upset and anxious. I can't stand the idea that while the virus is invading my body we are just sitting around doing nothing, letting it do what it likes with no opposition. It's terrible and absurd”.

M., 40 years of age

But even when it is looked forward to, the beginning can make people feel emotions comparable to those experienced immediately after the diagnosis

“I expected to feel relieved when starting the therapy and therefore starting to fight the virus. Instead, I again feel an endless anger and sense of guilt. I cannot see horizons or prospects. I feel as if I have gone back to when I had just discovered I was HIV-positive. And I realise that for those close to me this is hard to understand”.

N., 50 years of age

In the light of what has been said so far, it is to be presumed that more and more people with HIV, including many foreigners, will in the near future ask for clinical psychology interventions, not necessarily for problems related to the infection, but in situations where it will necessarily be present, even if only as background, and will be ready to come to the fore depending on how events develop. Health workers will therefore be called on to improve their training both on the question of HIV and also on transcultural matters.

It is to be hoped that they will increase their awareness of cultural, religious, social and political factors that have an impact on patients' lives, not interpreting experience and behavior according to their own system of reference, directly facing up to their prejudices, stereotypes and racist considerations. They will also have to make a translation and therefore a 'transduction', that is, learn to translate the patient's distress into their own cultural language and give back the message in a language the patient understands. The aim must not be to create a cultural health anthropology, but to identify ourselves with semiological, diagnostic and therapeutic practice in a situation of methodological uncertainty. As the psychiatrist Wang Bin (1991) states:

“What is the possible condition for mutual understanding between different cultures? It is the human capacity to mentally suspend certain concepts that are taken for granted and apparently universal for a culture and fundamental for its way of thinking, but for other cultures are relative and even irrelevant or extraneous”.

Lastly, keeping up to date is fundamental, as is supervision and assessment of interventions above all as regards HIV infection, the state of which is in constant evolution.

³ These are two progression markers. The first is the count of a subclass of lymphocytes targeted by HIV, the second is a number of copies of the virus per blood unit.

References

- Centers for Disease Control and Prevention (2003). Incorporating HIV prevention into the medical care of persons living with HIV. *Morbidity Mortality Weekly Report*, 52 (RR-12), 1-24. Retrieved June 22, 2009, from <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5212a1.htm>
- Colfax, G.N., Buchbinder, S.P., Cornelisse, P.G., Vittinghoff, E., Mayer, K., & Celum, C. (2002). Sexual risk behaviours and implications for secondary HIV transmission during and after HIV seroconversion. *AIDS*, 16 (11), 1529-35.
- Gielen, A.C., O'Campo, P., Faden, R.R., & Eke, A. (1997). A women's disclosure of HIV status: Experiences of mistreatment and violence in an urban setting. *Women's Health*, 25 (3), 19-31.
- Giuliano, M., & Vella, S. (2007). Inequalities in health: access to treatment for HIV/AIDS. *Annali dell'Istituto Superiore di Sanità*, 43 (4), 313-6. Retrieved June 22, 2009, from http://www.iss.it/binary/publ/cont/313%20-%20ANN_07_47%20Giul.1201519910.pdf
- Malcolm, S., Ng, J.J., Rosen, R.K., & Stone, V.E. (2003). An examination of HIV/AIDS patients who have excellent adherence to HAART. *AIDS Care*, 15 (2), 251-61.
- Martini, M., Di Pasquale, L., Cohen, G., & Pizzirani, A. (2004). *Responsiveness of Ethiopian community living in Italy to HIV/AIDS prevention material*. Paper presented at 15th International AIDS Conference, Bangkok, Thailand.
- Nachega, J.B., Hislop, M., Dowdy, D.W., Chaisson, R.E., Regensberg, L., & Maartens, G. (2007). Adherence to no nucleoside reverse transcriptase inhibitor-based HIV therapy and virologic outcomes. *Annals of Internal Medicine*, 146 (8), 564-73.
- Paterson, D.L., Swindells, S., & Mohr, J. (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Annals of Internal Medicine*, 133 (1), 21-30.
- Roberts, K.J. (2002). Physician-patient relationships, patient satisfaction and antiretroviral medication adherence among HIV-infected adults attending a public health clinic. *AIDS Patient Care and STDs*, 16 (1), 43-50.
- Serovich, J.M. (2000). Helping HIV-positive persons to negotiate the disclosure process to partners, family members, and friends. *Journal of Marital and Family Therapy*, 26 (3), 365-72.
- Spizzichino L. (2008). *Counselling e psicoterapia nell'infezione da HIV. Dall'intervento preventivo al sostegno psicologico* [Counselling and psychotherapy in HIV infection: From preventive intervention to psychological support]. Roma: Franco Angeli.
- Suligo, B., Boros, S., Camoni, L., & Lepore, D. (Eds.). (2009). Aggiornamento delle nuove diagnosi di infezione da HIV al 31 dicembre 2007 e dei casi di AIDS in Italia al 31 dicembre 2008 [Update of new diagnosis in HIV infection at the 31st dec. 2007 and AIDS cases in Italy at the 31st dec. 2008]. *Notiziario dell'Istituto Superiore di Sanità*, 22 (3 Suppl. 1), 3-23. Retrieved June 22, 2009, from <http://www.iss.it/binary/publ/cont/onlinecoa1.pdf>
- Temmerman, M., Ndinya-Achola, J., Ambani, J., & Piot, P. (1995). The right not to know HIV-test results. *Lancet*, 345 (8955), 969-70.
- Wang Bin (1991). Relativismo culturale e metametodologia [Cultural relativism and meta-methodology]. In A. Le Pichon, L. Caronia (Eds.), *Sguardi venuti da lontano: Un'indagine di transcultura*. Milano: Bompiani.
- World Health Organization (2004). *Gender dimension of HIV status disclosure to sexual partners: Rates, barriers and outcomes. A review paper*. Geneva, Switzerland: World Health Organization. Retrieved June 22, 2009, from <http://www.who.int/gender/documents/en/genderdimensions.pdf>

World Health Organization/UNAIDS/UNICEF (2007). *Towards universal access. Scaling up priorities HIV/AIDS interventions in the health sector. Progress Report, April 2007*. Geneva, Switzerland: World Health Organization. Retrieved June 22, 2009, from http://data.unaids.org/pub/Report/2007/20070925_oms_progress_report_en.pdf