

## *Living with HIV in the Dominican Republic*

Marivi Arregui<sup>1,2</sup>

INTEC University, Dominican Republic

### Abstract

This is a qualitative study based on the testimony of directors of organizations addressing HIV/AIDS and people living with HIV/AIDS in the Dominican Republic. Although the manifestations of stigma and discrimination related to HIV/AIDS have decreased in the Dominican Republic in comparison to past decades, ignorance and lack of supervision from government authorities foster that people with HIV do not receive adequate health services and the protection of their right to employment. Some groups are more affected than others as a product of the reinforcement of existing prejudices in the Dominican society, such as antihaitianism. Facing the changes in the spread of the epidemic I propose some reflections on gender and HIV, and suggest how to reinforce existing positive initiatives and the adoption of new ones.

*Keywords:* Acquired Immune Deficiency Syndrome; stigma; Dominican Republic.

### Viviendo con VIH en la República Dominicana

#### Compendio

Este es un estudio de carácter cualitativo, basado en testimonios de dirigentes de instituciones dedicadas a la prevención del VIH y personas viviendo con VIH en la República Dominicana. Aunque la manifestación del estigma y discriminación ha mejorado en la República Dominicana respecto a décadas anteriores, la ignorancia junto con la falta de supervisión de las autoridades hace que a muchas personas portadoras se les prive todavía de la adecuada atención en salud y el derecho al empleo. Unos grupos son más afectados que otros como producto del reforzamiento de los prejuicios existentes en la sociedad dominicana, tales como el antihaitianismo. Ante los cambios de las vías de expansión de la epidemia planteo algunas reflexiones sobre género y VIH, y sugiero cómo reforzar las iniciativas positivas existentes y adoptar nuevas soluciones.

*Palabras Clave:* Síndrome de Inmunodeficiencia Adquirida; estigma; República Dominicana.

*“The only way of accomplishing any progress is to substitute shame with solidarity, and fear with hope”*  
(Peter Tiot, UNAIDS, 2002)

In any effort being made to prevent the spread of HIV/AIDS it is evident that stigma and the associated discrimination are obstacles for prevention programs. The United Nation has stated so very clearly, when declaring that the third phase of the epidemic is indeed stigma and discrimination. In fact, this disease has undressed fears and prejudices society has concerning sexuality, pain, death, immigrants and poverty. Those fears are directly connected with ignorance about HIV and how it is spread. This ignorance makes people believe HIV carriers are a threat to society. Stigma is a way to identify and pointing out “threatening people” so they can be met with rejection, reclusion and elimination. Rejection has prevented HIV positive people from receiving basic rights, like health care and employment, so people with HIV hide their condition and stop going to health care centers and looking for jobs. HIV stigma and discrimination are a constant reason for

pain and sadness for HIV positive people and they contribute to silence, and as a consequence, the expansion of the epidemic.

#### Some Facts about the Dominican Republic

Dominican Republic shares two thirds of the island of Hispaniola with Haiti. It has a population of just a little more than 8 and a half million people, with an economy mainly based on tourism, duty free industries, and the money sent by Dominicans living outside the Island, for the most part in USA or Spain, an increasing population estimated in more than a million people. Even when the economy has had a notable growth in this past decade, superior to any other country in the region, the past ten years have also witnessed a huge banking sector crisis in which economic indicators have decreased, while inflation and unemployment increased (Rathe, Lora, & Rathe, 2004).

After Haiti, the Dominican Republic has the highest numbers in HIV prevalence in the Caribbean and Latin American region. According to the demographic and health survey of 2002 carried out by ENDESA (Spanish acronym for the Demographic and Health Survey), HIV prevalence is of 1% between the ages of 15-49. This percentage increases to 5% in populations living in *bateyes*, or sugar cane areas, generally a Dominican-Haitian zone. Geographically speaking, tourist oriented counties report higher numbers than others. The expansion of HIV has being increasing

<sup>1</sup> Dirección: arregui@verizon.net.do

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among women due to unprotected heterosexual contact. In 2003, retroviral therapy started very timidly with the support of international organizations like Global Found, the Clinton Foundation, and Columbia University. This effort has reached less than 400 persons, in comparison to the 8,000 persons who were supposed to start the treatment (Rathe et al., 2004). It is this scenario in which this study was carried out to explore manifestations of AIDS stigma from the perspective of key personnel in the HIV/AIDS related community.

### Method

This was a qualitative study and information was collected through interviews conducted by the author to key members of the community. The goal of the interviews was to record their perception of stigma and discrimination associated to HIV/AIDS in the Dominican Republic. The interview intended to explore differences in the manifestation of this phenomenon among population groups, and the expressions of rejection and discrimination in different situations, from individuals who internalize society rejections, to its impact in couple relationships and family, and the most hurtful form of stigma: discrimination in health services and employment.

Eight key members of the community were interviewed. They were selected according to their personal relationship with HIV issues, either they were themselves infected or impacted by people from different population groups living with HIV in their workspace. Specifically, there were two persons living with HIV, a man and a woman, both connected to the *Red de personas viviendo con VIH* (REDOVIH - Network of People Living with HIV) and members of support groups. The rest of the informants were people very close to the HIV issues that worked in institutions that offer services or some kind of support to HIV positive individuals. Their testimonies talk about their daily life experiences including:

- a. A female pediatrician in charge of the HIV/AIDS Program in a pediatric hospital, that also offers services in a shelter for orphans infected with the virus. She provided first hand information about the situation of HIV/AIDS among children in our country.
- b. The director of a non-governmental organization (NGO) situated in an intercultural community (different from bateyes) in which Dominicans live together with temporary Haitian immigrants. She gave us information about the immigrant Haitian population infected with HIV who lives outside the bateyes. There is a lack of documentation about this specific population.
- c. The director of the only NGO that provides support to the homosexual community of males. He is a source of information about stigma and discrimination associated to HIV/AIDS in this population.

- d. The director of a NGO that provides in prevention of HIV in a tourist oriented city. He gave us specific information about discrimination against people living with HIV/AIDS in hotels and the tourism sectors.

- e. A pastoral agent from an Episcopal Church gave us her testimony on the positive and solidarity-based approach that her church uses to develop HIV prevention strategies, and to work with people living with HIV/AIDS.
- f. Finally, we recorded the opinions of the country's representative to an international organization that works with HIV/AIDS, and who is responsible for developing health related policies.

The interview intended to explore in depth each of the informant's appreciations of stigma and discrimination associated with HIV/AIDS. It also dwelled into their experiences with these manifestations among different population groups, including differences between women and men. Through the interview I also explored the perceptions on how rejection and discrimination impacts private and public life. The interviewees were asked to make recommendations to deal with this problem.

We explained the purpose and nature of the study to all participants and their confidentiality was guaranteed. The interviewees who did not live with HIV mentioned they had no problems with including their names, and the names of the organizations they represented in the study. Every interview was recorded and then transcribed in order to analyze them according to established guidelines. A qualitative content analysis was carried out with all interviews in order to find patterns in the data associated to the objectives of the study.

### Results

The results reported here are widely confirmed by other researches. The Human Rights Watch report of 2004, confirms the status of Dominican women and the discrimination they are submitted to in employment and health services

#### Stigma Associated to HIV/AIDS does not Affect Every Group Equally

Rejection and discrimination does not manifest itself equally among all impacted groups. Stigma associated to HIV/AIDS reinforces already existing prejudices and rejection towards certain groups of people. HIV/AIDS strengthens stigmas and multiplies rejection, it also catalyses and leaves out in the open every existing prejudice in society. Some authors have stated, basing their opinions on the work of Foucault (1977), that stigmas deepen social inequalities making them seem reasonable (Aggleton & Parker, 2002).

Departing from what the interviewees said, we could establish a group scale for stigma associated with HIV in the

Dominican Republic. The most stigmatized groups are: Haitians, homosexual males, and sex workers. On the contrary, children can be put at the other side of the scale, being the less stigmatized group, but not exempt of discrimination. Within this scale metaphor, women from every particular population group are the most rejected by generic discrimination.

“If the person who has AIDS is a famous artist, white and blonde, there will be a wave of compassion and everyone would want to help him. But if she is a poor Haitian worker with skin ulcers... I think that this is like pulling up the curtain that hides existent strong prejudices. This situation strengthens what you already have inside”.

(Director of a NGO against racism and discrimination)

*Haitian Immigrants* - Racism and xenophobia are basic components in the construction of HIV stigma and discrimination (ONUSIDA, 2002), like any other stigma, where the rejected subject appears to be foreign. In the Dominican Republic xenophobia is regularly expressed in combination with racism primarily against the Haitian immigrant population. The Haitian immigration is widely used in the country as cheap labor force, a condition that makes them subject to constant violations of their rights, including the condition of illegal aliens. This fact is documented in the periodical reports on Dominican Republic from the International Commission of Human Rights, among other reports by various authors (see the excellent work on Haitian immigrants by Wooding & Moseley-Williams, 2004).

One participant pointed out the anti-Haitian prejudice which is combined with HIV/AIDS stigma held against this population, but there seem to be no solutions to their health needs:

“This is a country where there is a lot of prejudice against Haitians, a country full of racism. It is not only anti-Haitian, it is racist. You can imagine what it means when you can hear people saying Haitians have AIDS besides being black, besides being illiterate, besides being Satanist and Voodooist... The problem is that AIDS is spreading among this population, and we are doing nothing to prevent it, because we don't offer them health services”.

(Director of a NGO against racism and discrimination)

*Men who have Sex with Men (MSM)* - Homophobia, so rooted in our society, strengthens rejection towards HIV positive MSM. With only the suspicion that a patient is a MSM, the doctor orders an HIV test. The pastoral agent we interviewed compares the situation in the Dominican Republic to what she has seen in other countries:

“Here in the Dominican Republic... they are discriminated against because they are homosexuals, but also because they are positive. Then the drama is worse, because what we have seen in New York or France is that there is acceptance. Discrimination against homosexuals in those countries is not like here, here is seriously homophobic, so here the weight is more unbearable”.

(Pastoral Agent)

*Children* - There is no data on the specific number of HIV infected children in the Dominican Republic. Since 2000,

vertical transmission has been reduced significantly, but not completely, when most hospitals implemented *Nevirapin* treatment for HIV positive pregnant women.

According to testimonies recorded, children are the least blamed group since most of them got infected via vertical transmission. There are certain cases that in the testimonies come across as making references to children born out of a rape, or due to prostitutes' relationships with foreigners (Arregui, 2004). Nobody blames them, but they are still rejected.

The pediatrician, through her experience with her patients knows exactly what happens in this field:

“At schools, if they say they are HIV positive they are forbidden entrance, maybe by ignorance of some professors and directors. They say it is because if other children know they all will leave, especially in private schools. It goes as far as not wanting the HIV positive kid to play with other kids, etc”.

(Pediatrician)

She also narrated how some family members don't want to take care of children when they become orphans, because they find out they are infected with HIV:

“(With children) it is more difficult to see rejection, it is very rare to see someone rejecting a baby. The manifestation comes when the parents die, or at least one of them. The baby goes to live with a grandmother, or an aunt, a cousin, or neighbor, and they stop helping saying they don't have money to take care of him/her... That's the excuse: 'I don't have any money'. If he or she wasn't infected, they would”.

(Pediatrician)

There is more to the rejection than just fear of being infected, as the doctors points out, it is very difficult for poor people to take care of the young infected kids. In most cases they are grandmothers in poverty, who realize the special needs of their “sick” grandchildren and know they will spend a lot in health care. These grandmothers also think the help they can provide will be useless in the future if they become teenagers. The State or private institutions are no good in taken care of these HIV positive children. Therefore, families are forced to take care of the children. As poor as they already are, they have to take them into their homes. Báez (2003) documents the dramatic situation lived by these orphan HIV positive children in the Dominican Republic.

A woman living with HIV gave us her testimony, as she narrated how stigma not only affects people living with HIV/AIDS, but also their children. Her son, who is HIV negative, has been rejected at school because she is HIV positive:

“Kids, neighbors... the other mothers tell their kids: 'don't play with him, because his mom has AIDS'. That's very traumatic. My son has had a lot of problems because of that”.

(Woman living with HIV)

*Women* - Power relations between women and men are an important factor that puts women in a very vulnerable position in terms of risk of infection, because they feel they cannot refuse to have unwanted and unprotected sex.

Women are the most blamed if they get infected, and they suffer more discrimination than men. This situation becomes more serious when the number of women infected by their heterosexual partner is increasing.

“Women have to deal with accusations of being prostitutes, unfaithful, and other things that our chauvinistic society permits to men”. (Medical director of a NGO in a tourist area)

“With all the moral precepts that we impose on women, it is more difficult to accept that she is infected, moreover if she is a young woman. Everything that a woman did is being judged, her life, if she is married or not, and how she was infected. That’s what’s less accepted”. (Director of a NGO against racism and discrimination)

#### Manifestations of Stigma and Discrimination Associated to HIV

People living with HIV witness how their whole life, private and public, is affected. Rejection and discrimination are manifested, first as internalized stigma and in their significant other relationship, then among family relations, community, schools, and, above all, health centers and the workplace.

*Self-Hatred:* The first scenario affected by rejection and stigmatization associated to HIV/AIDS is the self image. An HIV positive person first reflects every prejudice and rejection learned in society onto himself/herself. He or she is flooded with rational and irrational fears. Fear and silence take control over the life of the person recently diagnosed with HIV. Fears clouds over the possibility of being recognized as an infected person, so he or she tries to hide what others don’t know. The person is silent and afraid to tell others about what is happening. Sometimes they keep the secret even from their significant other. They experience suffering that could be mitigated if HIV/AIDS was socially approached differently as a health condition and not as a shameful and terminal illness.

“I cloistered myself, I wasn’t even going out for groceries, and I cleaned around a little, and then went back to confinement. I became very timid. I would go to my mother’s, sit down, and then go back home, and seclude myself from everything”. (Women living with HIV)

Stigma has a corrosive power upon people living with HIV/AIDS. It is well known that emotional depression deteriorates physical health reducing immunity (ONUSIDA, 2002). For people living with HIV/AIDS, fears and silence also have effects on their emotional and physical health. A woman living with HIV gives an excellent explanation of the dangerous effects of discrimination in the health of patients:

“I think that what really kills a patient is discrimination... The opportunistic illnesses come because of the sadness ones suffers, that decreases the CD4, and increases the viral load up to a million”. (Woman living with HIV)

The reactions of Haitian immigrants deserves special attention:

“They deny it and say “that’s not true...that’s the Dominicans willing to say we Haitians are infected with

AIDS, I will go to Haiti and they will give me a homemade cure, that’s a voodoo job someone sent me...”. They have a series of taboos, of strong resistance to accept it and understand it. When symptoms start to appear and they become really sick, then they accept it, they go through a resignation phase, of suffering, they never complain too much. I would say that around 10% accept and understand clearly what’s happening to them”. (Director of a NGO against racism and discrimination)

The interviewee talked about a particular Haitian population, who are poor and illiterate and come to the country as cheap labor force. The denial of the illness isn’t exclusive of HIV/AIDS or Haitians immigrants. We humans tend to believe that ill fate and illness are things that can’t happen to us. In the case of AIDS, denial and rejection to people living with HIV/AIDS trigger this type of reaction.

#### Alternatives to Fight Fear and Silence

In the interviews it became evident that counseling strategies, like support networks for people living with HIV/AIDS, are powerful weapons to destroy fear and silence. When a positive diagnosis is obtained together with information about the virus, how it can be transmitted, how it works and behaves, and when it is possible to receive that information from an HIV positive person as well, the newly diagnosed will also understand that the world has not come to an end. Counseling helps to decrease fears of death and prevents seclusion and confinement. This is the testimony of a HIV positive man in counseling:

“I took it easy when I got the results. The ideas of committing suicide and disappearing were gone. I went on with my normal life”. (Man living with HIV)

Support groups, where people living with HIV and their families openly talk about AIDS, along with the existence of networks for people living with HIV that are not afraid to go public and talk about their condition and fight for their rights, have a huge impact on the lives of HIV positive people.

“She told me: ‘welcome, welcome to the family’ and I went in. They welcomed me with a lot of love... I kind of thought that HIV... ok, it is an illness, but there were so many people more or less like me, that were very happy. Why couldn’t I be as happy too? I can continue my life being very happy”. (Woman living with HIV)

#### The Couple: Reflections from a Gender Perspective

Rejection due to HIV also can be seen in couple relationships, where power dynamics are already in struggle. Aggleton and Parker (2002) have documented differentiated attitudes due to gender in developing countries.

Once a positive diagnose is announced, it is suggested to the patient that he or she talk to their partner, in order for them to be tested also, since in most cases the virus has been transmitted sexually. Our interviews show that both women and men are resistant to be tested. In the case when both partners are positive, frequently they start blaming each other because of

who is primarily responsible. Fear of being blamed, or even losing the partner makes seropositive people remain in silence, and not to talk to their partners about it. On this matter the pediatrician we interviewed said:

“If a woman comes to me, I advise her to ask her husband to be tested...but she never gives him the message. She is always afraid, “if I tell him he will kill me”. I say: “If you haven’t had any other relationships, then he did”. “Yes, but you know, he is too aggressive...” There are worst cases. Women get married knowing they are infected. There are a couple of cases in which the husband dies or they get divorce and soon after she starts a relationship with someone else. She gets married again without telling the new husband she is infected”. (Pediatrician)

This testimony states a very important and fundamental topic in the knowledge of how the virus is transmitted. In one hand, it makes evident a behavior others authors have described (Báez, 2003) as *sequenced polygamy*, referring to the multiple relationships that people establish, especially in the popular or lower classes. This behavior, rooted very deeply in our societies, constitutes a very important risk factor in the transmission of HIV. On the other hand, it makes women vulnerability even more obvious: “It is typical in our countries that if a poor woman gets divorced, she will not remain alone for long. Daily survival is very difficult, since in most cases husbands play a role of authority and principal money provider, although this last one is more symbolical than real. Husbands do the same: one woman after another...and it is also typical in our country that a man, while having a more or less stable relationship with a woman, still goes out and has sexual relationships with other women more or less continuously. Most of the time not using condoms” (Báez, 2003, p. 50).

The power inequality among women and men is traduced as a higher vulnerability risk for women getting infected by HIV. There are authors that have established that most of the women get infected not as results of their own risky behavior, but those of their partners (Brofmann & Herrera, 2002). Recent studies in the Dominican Republic about women and the use of condoms show the difficulty women have to introduce condoms in their sexual relationships with their “trustful partner” because they don’t want to make them mad. The demonstration of “love” toward their partner comes first than the responsibility of protecting themselves (Báez, Félix, & Martínez, 2004).

In cases where only one of the partners is infected, we could see different gender related reactions. In heterosexual couples, the behavioral pattern that comes across the interviews is like this: if the woman turns out positive and the man negative, he leaves her while accusing her of unfaithfulness and prostitution. If the man is the one positive, she will remain with him and provide care without abandoning him.

“We say that being a poor woman in the Dominican Republic is a risk on its own, without any other conditions.

Dominican women are very submissive in a couple relationship... women are very dependant, economically, mentally and emotionally, and even more so if there are kids, it’s very difficult then for them to leave the relationship. In the reverse case, if she is the one that is sick, and the man is not, he would leave her and accuse her of prostitution and all the thinks imaginable”. (Physician and director of a NGO in a tourist zone)

This behavioral pattern, worsened by poverty, is seen in both poor Haitian and Dominican communities:

“If women shows symptoms first, and if it is a Haitian family, the man notices the woman is getting sick – sometimes he does not even know it’s AIDS- and starts saying the woman is “hazardous”, that she makes him spend too much money in medicines and she doesn’t get well...and then he leaves. Sometimes even pregnant and or with a couple of kids. But, if the woman discovers that her husband is sick, she stays and works like crazy seeking money to give him his medicine, until his death. A lot of times when the man dies, she would go back to Haiti”. (Director of NGO against racism and discrimination)

“In the Dominican couple, it’s the same. At the end it is how it works in every couple. He is the one who gets his wife infected – at least this is what happens here- and then it is the woman who forgives everything one way or the other. Furthermore, she would have an attitude of continuous help for him, keep serving him, making him her reason to live”. (Director of NGO against racism and discrimination)

What is happening in my country makes me wonder. It is the man the one that “carries the virus”? At least that is how people around here refer to it, and how international surveys insinuate. The social conditions influenced by gender tolerate and encourage men to have extramarital relationships, and also repress them of having open men to men sexual relations. This contributes to concealed homosexual relations and as a result we are seeing more and more men becoming infected, and then carrying the infection to their wives. The social gender conditions imposed on women are also important in this equation, since women are being infected by their husbands or significant others. Women will tolerate infidelities that can place them at risk, and they don’t protect themselves sexually. At the rate women are being infected, there will be more women living with HIV/AIDS without a partner everyday.

The speed at which the virus is spreading among Dominican women shows the need to pay attention to the cultural and economical elements that influence their vulnerability to infection. The possible measures to control the transmission of the virus confront questioning from predominant patterns of masculinity, and women empowerment at different levels.

#### Family: From Rejection to Solidarity

In most cases, family members of the person with HIV/AIDS are also targets of social rejection, facing the same discriminatory attitudes. According to our interviewees the

situation has changed in comparison to past years when families did not even receive them, and patients would die on the streets after being rejected from hospitals and homes:

“One of the reasons (for which our institution was founded) was because gay people were being rejected... a lot of gay men were dying on the streets of Santo Domingo because they were rejected at the hospitals, and they were kicked out of their homes. Rejection has been decreasing comparing it to past years...but, the fact that families have become more responsible in taking care of AIDS patients, doesn't mean stigma inside the house has been erased. Stigma prevails when the patient is isolated in a separate room, regularly in the back room, and when they are not allowed to have visitors so that people don't notice that he/she has AIDS”. (Director of an NGO supporting MSM population)

When a family accepts to take care of its infected family member, women show more comprehension and tolerance. They are usually the ones in charge of the ill. Interviews show cases in which a family supports and protects its family member emotionally and economically. This was the testimony of a man that receives money from his brother who lives overseas:

“I am lucky to have brother overseas. He never forgets about me, and he once told me “you just have to call me, I will solve any problem”. In that sense I am all right. He said to me “don't you worry, you will have my help until you find something”. (Man living with HIV)

#### Community

The shameful mark that still prevails upon HIV is clearly seen in the relationships inside communities, urban or rural. The smaller the community the less possible it is to be anonymous. Therefore there is a greater possibility that the HIV positive person is identified and stigmatized. An informant working among the Haitian community explains the rejection toward certain people:

“We had a case, a woman that returned to Haiti. She was a symbol of stigma. I mean, HIV positive, poor and female... she really had to leave places. After being a couple of months in a place, when they figured out or even insinuated that she might be ill, she had to go. Here they rent washing machines so people can use them at home. She couldn't rent them, people just didn't rent them to her”. (Director of a NGO against racism and discrimination)

#### Solidarity from Churches

The work done in some churches is worth mentioning. It is prevention work in which HIV positive people get involved so they can give out information about the virus and how it is transmitted. They also prepare the general community to help them accept and welcome people living with HIV/AIDS inside the community:

“When the community learns more about the virus, and they get to know about the suffering of the people that already have the virus, then we ask them: “What is God

telling us with this experience, with those human beings?”

When the workshops are over, people are more sensitive, and when they have to deal with a person living with HIV/AIDS, they deal with them in a normal manner, because they no longer fear them. That's the issue, fear, we have to make fear to go away”. (Pastoral Agent)

This pastoral work, based on compassion instead of damnation offers hope in efforts to eliminate stigma. The different churches that exist today are very influential in our society. Their messages are well received and accepted by a great portion of the population. In the same way that other religious discourses get through to people from the pulpit, making them believe that HIV is a punishment from God, and that people living with HIV/AIDS are suspicious of deviant sexual behavior, this compassionate religious approach can contribute and encourage acceptance of the ill and the HIV positive. Furthermore, this approach has a deeper biblical foundation than that of the damnation since compassion mimics Jesus's behavior towards the Samaritan (Jn 4), the adulterous (Jn 8, 1-11), the leprous (Lc 17, 11), and other stigmatized people of His time.

#### Having HIV/AIDS and Going to a Hospital

In order to explore how discrimination manifest itself in health centers across our country, we asked the interviewees about their knowledge on the matter, either by personal experiences or stories told to them by people living with HIV/AIDS. According to them, discrimination associated to HIV/AIDS among the health sector has decreased significantly in comparison to past years. But, still today, either in public or private health centers, there are clear discriminatory practices that prevail even when they are well known violations to basic human rights of people living with HIV/AIDS, or when they go against the laws or the international agreements signed by the Dominican government. Discrimination at hospitals, along with rejection of employment, is the greatest expression of stigma and discrimination associated to HIV/AIDS according to our key informants. The testimonies we present here, are widely supported by other reports like the *Human Rights Watch* (2004), and Báez's (2003) report on children's vulnerability to HIV, both previously quoted.

A summary of the most common expressions of discrimination described by our informants are the following:

a. Open rejection, or excuses from health professional to reject clients.

“In specific departments, like neurosurgery, otorhinolaryngology and thoracic surgery they won't treat these kinds of children... we still don't have a professional willing to perform a bronchoscopy. They always say there is no bronchoscope, or that it is broken... That is the experience in every hospital, not only here. Also in intensive care... in order for them to accept a patient there, they do it with resentment; they would say:

“sidosos”, that’s the diminishing word they would use: “why would you even treat ‘sidosos’, they are going to die anyway”. (Pediatric Doctor)

“From the moment they know a patient is HIV positive, their attitudes change, even when there are capable health professionals to take care of these patients. It changes during labor... if a caesarean is necessary, the gynecologist disappears, nobody wants to deal with a patient like that”.

(Doctor and director of an NGO in a tourist zone)

We suppose these attitudes are individual behaviors and not hospital policies, in which case they would be in open violation of Law 53-93. In any case, these attitudes toward HIV positive individuals are tolerated by the hospital administration, that are not supposed to ignore this type of rejection that does not save lives that could be treated with antibiotics, or that prevent the patient from being tested further so they can receive a better diagnosis.

b. Subtle forms of rejection included placing patients in wards where there are other contagious patients and when health professional are extremely precautious because they found out they are dealing with an HIV patient. The woman living with HIV gave us a dramatic testimony.

“One time I was poisoned by seafood, I was taken to a public hospital. Because I am a conscious person, I saw that the doctor who was going to inject a serum in me wasn’t protecting herself that much, so I told her: “Listen I am HIV positive, wear gloves, protect yourself a little”. Ah! The doctor wore three gloves. She put me in a stretcher far away, where there was a hepatitis patient that was completely yellow. To my other side there was a tuberculosis patient that couldn’t breath. I felt so bad that I didn’t let her give me the serum. I told her ‘doctor... why don’t you bring a bottle of turpentine, find a needle and inject me 10cc of it... the way you are discriminating against me, you are killing me. I feel I am dying inside”.

(Woman living with HIV)

This woman compares discrimination with death in a very lucid way. The way she was treated was worse than being injected with turpentine. She even had the courage to express how she felt to the doctor who was treating her badly. These attitudes demonstrate how health professionals’ lack of information fosters the perspective of the patient’s condition as a death threat, and blames the positive person for any risk of contagion making the patient feel like they are “dying inside”.

c. Some health professionals order HIV test to be performed on patients without their consent, even when Law 53-93 prohibits it. This is a common practice when the physician assumes the patient is homosexual, a group already stigmatized in relation to HIV.

d. Hospital personnel do not respect the confidentiality of the test results:

“We have testimonies from communities... in which for example, the person running the test makes comments like ‘Such and Such is infected, or Such and Such is taken’. Then there is fear in that community... they rather go to

the capital, or to San Pedro de Macoris to be tested for HIV, instead of being tested in XXX because there is no warranty of confidentiality whatsoever”. (Director NGO in support of MSM)

This same informant mentioned:

“Frequently we receive people that get to know about their positive diagnoses because the laboratory gave the results to their parents”. (Director NGO in support of MSM)

The lack of confidentiality in laboratories and from health professionals prevents anyone from following any recommendation given by the Pan-American Health Organization who encourages people to get tested for HIV (Organización Panamericana de la Salud [OPS], 2003).

e. Lack of access to antiretroviral treatment for most of the population is an urgent problem. The fact that most of the population has no access to antiretroviral therapies that have changed the lives of many, drastically reducing the number of deaths associated with AIDS, is also a form of discrimination. The antiretroviral (ARV) program originated in 2003 has a very limited reach, and it is mostly funded by international sources.

f. Heightened discrimination in hospitals towards several groups is common. Although every person living with HIV/AIDS can be an object of discrimination at health centers, some groups are more vulnerable than others. Hence, poor people are subject to greater rejection, along with more stigmatized groups like Haitians immigrants, prostitutes and homosexual men. This stigma is manifested even when health professionals only suspect they belong to one of these groups. The most dramatic situation is lived by Haitian immigrants. Some NGOs and religious institutions have developed programs like “Solidarity Companionship”<sup>3</sup> to accompany HIV positive persons when they have to go to a health centers and ask for services. For population groups as discriminated as Haitian immigrants, whose situation is worsened due to the language barrier, most of the times these programs are the only way people living with HIV/AIDS are actually treated at health centers.

“In XXX Hospital, if they go on their own it gets very difficult. The thing is that we have relationships with international organizations, with projects; we are capable to denounce it. If we go with them, especially in that hospital, they get served. Some people do treat them just because, other do it because we accompany them”.

(Director of an NGO against racism and discrimination)

The way they discriminate against people living with HIV/AIDS in some Dominican hospitals is a clear violation of their human rights. Discrimination is responsible for the death of many patients due to opportunistic diseases that could have been treated with the proper medicine. At the

<sup>3</sup> This is the name of an NGO program that accompanies people living with HIV/AIDS to health centers.

same time, it also causes patients to decide not to go to health centers to ask for treatment so they won't be exposed to humiliation from health professionals.

Still, not all is lost. There are many testimonies that account for positive experiences at health centers. Many health professionals, in public or private hospitals, are sensitive to the needs of people living with HIV/AIDS, a fact that is well recognized by some patients who go health professionals who are friends of family members as an alternative to prevent discrimination.

#### Having HIV and Looking for a Job: Employment Discrimination.

Employment discrimination due to HIV is not an exclusive phenomenon happening in our country (Aggleton & Parker, 2002; Organización Internacional del Trabajo [OIT], 2001). It is a complex phenomenon in which economic and social implications are interconnected with AIDS stigma. Employers fear an increase of their health insurance coverage policy, and the alleged decrease of employees' performance in the workplace. This is added to the lack of information on HIV that leads to believe that clients and other workers at the workplace are at risk of getting infected by the person living with HIV. People living with HIV are not only being fired from their jobs, but they also have problems accessing new jobs because of discrimination against them. Both situations are part of the context of a country in development in which there is more work force than jobs, a context in which violations of labor laws are frequent.

When asked, our key informants reported about their own experiences in the workplace, or that of others. Their testimonies were impressive. Stigma and discrimination associated with HIV/AIDS in the Dominican Republic have a direct effect on the employment status of people living with HIV/AIDS, especially those without skills. Paying jobs are denied to people with HIV, and therefore their economic and emotional situation is worsened.

Stigma manifestations are obvious when employers illegally ask their employees, and those applying for jobs, to get tested for HIV. As a result, positive employees are fired, and new jobs are denied to those who apply for them. The testimonies we recorded make open references to the tourist and manufacturing industries, the last one called manufacturing zone.

"I only knew how to sow in a manufacturing zone...but they ask you for a complete blood count, and there they run the HIV test. From the moment they see you have tested positive to HIV they tell you 'we are not going to need you'. That is very depressing... You can't get a job anywhere". (Woman living with HIV)

Testimonies recorded account for employers that do not tell their employees the results of the HIV tests, because that would entail accepting that they are proceeding against the laws of consent. In these cases, employers have a

mechanism that could prevent other people from getting infected. Still, they don't use it because they are more interested in their economic profit and their intention is to get rid of these employees that could cause them economic losses and low performance rates.

"The Law 55-93 is broken. In hotels and in manufacturing zones, everywhere, they test their employees and then they don't tell them the results. If an employee is HIV positive they wait for the first mistake they do to fire them. Employers from different workplaces exchange the list of names of HIV positive employees. That's how, HIV positive workers can't get jobs anywhere". (Physician and director of an NGO in a manufacturing zone)

"We have a lot of dancers that have been fired from the tourist industry, from hotels in Bávaro, in Juan Dolio, in Puerto Plata...most of the times they are from small towns, from rural areas, sadly enough these guys have to go back there to die". (Director of a NGO in support of the MSM population)

When labor laws are broken and human rights are violated like this, the impact in the lives of people living with HIV/AIDS is enormous: poverty and emotional distress. Many of them lose their job, and therefore lose their only source of money. Báez (2005) states that the relationship between HIV and poverty is very clear. Bronfman & Herrera (2002) concluded that: "A household impacted by HIV/AIDS, where one or more of its members are infected, lives not only a great human tragedy, but also an economic crisis. The cost of health care expenses increases very rapidly" (p. 75).

This situation is worsened when we assess the alternatives to deal with employment discrimination. In this context, contrary to the access to health care services where there are some centers or health professionals willing to give quality services to people living with HIV/AIDS, there are almost no alternatives in the workplace. When confronted with the lack of employment, some take very risky exits:

"We worry for the transvestites that have to become prostitutes. For a gay man living with HIV, sometimes there is no other solution to unemployment than prostitution. They can't find a job anywhere else, so they are out there selling sex, and we are not sure what is their level of protection". (Director of an NGO that supports the MSM population)

The lack of community efforts to fight for their rights of the marginalized leave employers unpunished. Still, our key informants reported that sometimes suing them, or even threatening them with suing, has made employers reinstate employees fired because they were HIV positive. This could make us think that in the fight against discrimination associated to HIV/AIDS, we need to get more involved with the judicial branch of the governmental system, especially to deal with employment issues. We can't forget that in order for a person to go to court to fight for his/her rights, they have to go public about their condition, a decision that people living with HIV/AIDS might not be empowered to make.

In order to prevent that employment discrimination goes unpunished in the country, state officials have to be more vigilant of the implementation of labor laws. Strategies must be developed to make employers, and the media, more aware and sensible to this issue. This should be done in collaboration with the networks of people living with HIV/AIDS, so they can continue defending their rights. All this is needed so discrimination in the workplace can be eliminated.

### Conclusions: Some Suggestions to Fight Stigma and Discrimination

Although many of our interviewees stated the situation is better in comparison to years past, they also mentioned that stigma and discrimination associated to HIV is still very predominant in the Dominican society. According to key informants, this is a situation that deeply affects the quality of life of HIV positive individuals, becoming an obstacle to the prevention of the epidemic.

Interviewees gave us several suggestions of actions to take in order to change the current situation. The mentioned strategies could very well be the foundation for a national HIV prevention plan:

Our key informants *asked for political willingness from state officials in order to stop the spread of the virus*. Some of the interviewees asked politicians to talk openly about HIV and AIDS, in order to fight the silence that minimizes and conceals the real situation of the disease.

Unanimously, the interviewees *reclaimed that state officials should become alert about the situation so that in every public health center people with HIV/AIDS can receive quality services*. It is urgent that health professionals have updated information about the virus, and that discriminatory practices are censored and supervised. They also asked for the availability of more treatment therapies, such as antiretroviral treatment:

“Although there have been changes, the true changes are going to come when access to treatment becomes the norm, when people get cured, when people get treated, when they see it is possible to live with HIV”. (International Organization Director)

The interviewees unanimously stated the need to *increase HIV/AIDS educational campaigns* with information on facts on transmission methods and services for people living with HIV/AIDS. These campaigns must reach every sector of the population, including Haitians immigrants. Information should get to far away places where television and electricity is still unavailable.

*They mentioned the need to fight employment discrimination that makes people living with HIV/AIDS lose their only source of income*. It is very important that state officials impose the current labor laws and international agreements upon employers. It is equally important to

develop strategies to make those employers more sensitive to HIV issues, and to empower networks of people living with HIV/AIDS so they can give support to those affected by discrimination and keep fighting for their rights. It is very convenient to spread the word on successful stories of people living with HIV/AIDS, so they can serve as examples for employers and even other HIV positive individuals.

*Interviewees also mentioned the need to foster a gender perspective on the matter*. The increasing rate of women infected with HIV requires approaches from different perspectives in order to develop prevention strategies that take gender inequalities into consideration. It is particularly important to build strategies based on the empowerment of women in their relationship with men, and also encourage them to be economically independent.

*Active participation of people living with HIV/AIDS in the search for better solutions was also an important topic mentioned*. Some people suggested the integration of people living with HIV/AIDS to the policy making process as “part of the solution” (UNAIDS, 2002). This suggestion also included inserting them in health center committees, and being the main advocacy groups to support their rights:

“I think that everyone working with HIV, every counselor working with HIV, has to be positive, so they know. Because that person is living with HIV too, and can give better advice, and increase self esteem in other HIV positive persons...There should be at least one HIV positive person working in every hospital...it hasn't been done yet”. (Woman living with HIV)

*Finally, the need to replace judgment and damnation in the church with solidarity and compassion was also mentioned*. Interviewees made a special call to churches so they can raise their voices and take a stand on HIV/AIDS issues with a pastoral approach that encourages solidarity and compassion towards HIV positive individuals. This should replace discourses that describe HIV as a punishment from God, and condemn people for their sexual behaviors.

There is much to be done to eradicate the stigma surrounding HIV/AIDS in the Dominican Republic. I hope the verbalizations of the key informants in this study shed light on the potential roads of action to achieve a stigma free society.

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**Mariví Arregui.** Masters degree in Gender and Development, with studies in philosophy, and psychology. She has engaged in several studies on evaluation of services for people living with HIV/AIDS in the Dominican Republic. She is a member of the advisory committee of the Center for Gender Studies at the INTEC University.  
E-Mail: arregui@verizon.net.do