

DOMINICAN REPUBLIC: STIGMA AND DISCRIMINATION IN PEOPLE LIVING WITH HIV

Executive Summary

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with the collaboration of:

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and the participation of:

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INTRODUCTION

The data shown in this report originate from a study conducted in the Dominican Republic by Profamilia with the cooperation of REDOVIIH(+) and ASOLSIDA, using a tool developed by the International Planned Parenthood Federation (IPPF) in collaboration with the Joint United Nations Programme on HIV/AIDS (UNAIDS), the Global Network of People Living with HIV/AIDS (GNP+) and the International Community of Women Living with HIV/AIDS (ICW). The purpose of this data collection mechanism is to develop an index that can be used as a tool in advocacy work, the promotion of human rights and to address stigma and discrimination.

To conduct the study, a sample of 1,000 people living with HIV (PLWH) was selected at the national level, distributed in four regional geographic areas (Santo Domingo, Cibao, Southeast and Southwest) in order to provide results with a certain degree of area segregation.

1. SOME BASIC PERSONAL CHARACTERISTICS

The group of individuals included in the study shows an almost equal distribution by sex: 48.6% males and 51.0% females. Also, 0.4% identified themselves as transsexuals. Approximately 10% are young people and the largest group (38.4%) is concentrated in the segment of young adults (30-39 years of age).

In addition, the study population has relatively low levels of education, with a mere 6% having attended universities; unemployment affects 43.2% and 70.9% of their households have an annual income below 3,000 dollars.

2. STIGMA AND DISCRIMINATION BY OTHER PEOPLE

The types of discrimination most frequently perceived by the respondents are those associated with gossip (62.3%) followed by verbal aggression (29.7%) and harassment or verbal threats (26.8%), harassment and physical threats (13.8%), exclusion from family activities (11.4%), physical violence (10.5%) and psychological pressure from their partners (9.9%). In general, these forms of discrimination affect more women than men.

Some of the main reasons why people living with HIV feel rejected include: a) the fear of transmission through casual contact (30.3%), b) people think that being HIV positive is shameful and so they should not mix with him/her (16.9%) and c) the actual fear of people of being infected with HIV (11.8%).

3. GENDER BASED VIOLENCE

In terms of emotional violence, 30.9% of the women interviewed had been subject to either verbal or physical humiliation by their partners, while 23.9% had been threatened with physical harm either to themselves or someone close to them. At the same time, in terms of physical violence, almost one out of three women interviewed (34.2%) have been pushed, shaken or have had some object thrown at them, while in 28.4% of the cases they had been slapped or had their arm twisted; 24.5% have been punched with the fist or something that could have injured them and 11.1 % have been assaulted with a weapon. The common background for these forms of violence is the fact that more than half of these women (52.6%) have been subject to some type of battering since the age of 15.

4. ACCESS TO WORK AND HEALTH SERVICES

A clear demonstration of the denial and violation of the rights of people living with HIV is the fact that in the last year, 20.6% of the respondents have been forced to change homes or have been denied the rental of a house or apartment, and in 42% of these cases the cause was associated with their HIV status.

The loss of employment or other source of income during the last 12 months affects 17.2% of the respondents, and of these more than 20% acknowledges that the reasons for losing a job or other source of income were associated with their HIV status.

In this scenario of deprivation of rights, almost 10% of the people interviewed had been denied employment at least once in the last year (9.7%) and (8.4%) had been denied health services, including dental care, because of their condition of person living with HIV.

5. INTERNAL STIGMA AND FEARS

During the last 12 months, approximately one third (31.0%) of the respondents have felt ashamed; 30.0% feels guilty; 34.4% blames him/herself; 35.4% blames others and 30.8% has a low self esteem. These feelings and expressed in differing levels of intensity depending on the gender. Hence, self blame is higher in men (33.3% feel guilty and 40.3% blame themselves) than in women (26.9% feel guilty and 28.8% blame themselves).

Similarly, feeling shame (38.8%), blaming others (48.2%) and having a low self esteem (3.1%) is found with greater emphasis in women than in men (23.0%, 21.8% and 25.5%, respectively). Other traits that are more common among women include not attending social gatherings, isolation from family and friends,

not applying for a job or a work promotion, not marrying, not having sex and not having children. Women also are more likely to feel afraid of gossip, of being insulted or verbally threatened, harassment or physical aggression and of being battered.

6. RIGHTS, LAWS AND POLICIES

At the national level, there are two important instruments associated with the rights of people living with HIV: The Universal Declaration on HIV/AIDS and the AIDS Law 55-93. But in reality, less than half of the people interviewed (45.8%) has read or heard about these two documents and among those who have, only 59.3% has ever read their contents. Even in the case of Law 55-93 that is local, only 69.2% has heard of it. This indicates that almost 31% of the individuals in the study are unaware of the existence of a document which, aside from being highly important for them, has been subject to debate and frequent media coverage for several years.

The degree of knowledge on these documents is higher among women; 48.2% knows about the Universal Declaration on HIV/AIDS versus 43.2% of the men. Also, 73.3% of the women have heard about Law 55-93 versus 64.8% of the men.

23.1 % of the persons interviewed admitted that in the last 12 months at least one of their rights had been violated as people living with HIV. However, only 10% in this group sought legal compensation for the offense. Being a woman reduces the possibilities of seeking legal compensation of the damages caused by a violation of her rights. Only 8.0% of the women sought legal compensation, while the percentage was 13.3% in men.

7. CHANGE MANAGEMENT

A significant portion of the people interviewed actively participates in actions addressing change. During the last 12 months 35.3% has confronted, questioned or educated those who have discriminated or stigmatized them; 73.6% has given support to others with the same health condition; 58.2% belongs to a group or network of people living with HIV and 14.4% has participated in efforts to develop laws, policies or guidelines associated with HIV.

Likewise, 25.6% has participated in local projects oriented to benefit people living with HIV; 20.4% has participated in national programs and projects in favor of people living with HIV and 15.5% has been involved in legal issues that affect those who are living with the virus.

8. TESTING AND DIAGNOSES

The main reasons for having an HIV test are: being referred based on suspected symptoms of HIV infection (28.8%); a positive HIV result in your partner (17.4%) and a voluntary decision to be tested (12.8%). These three reasons, in the same order of importance, drove men to having a test (34.8%, 20.0% and 16.3%, respectively).

In the case of women, the main reason for being tested was the recommendation of a physician based on their pregnancy (29.8%), followed by a referral based on suspected HIV symptoms (21.6%); a positive result in the partner (15.1%); the disease or death of a partner or a family member (10.8%); and a simple wish to know their HIV status (9.6%).

In one of every four cases (74.9%), the decision to have an HIV test was voluntary and two out of five (42.9%) received counseling both pre and post receiving the test results; while one out of four (27.0%) did not receive counseling at any time, with a higher percentage of women (30.0%) than men (23.9%).

9. DISCLOSURE OF THE HIV STATUS

In more than one fourth of the cases (26.3%) the adult family members found out the respondent was HIV positive through other people, and almost three out of four children in the family (71.8%) were unaware of the situation. The greater willingness to reveal their health status is precisely when the interviewer is a social worker or a counselor (84.9%) or a health worker. These were directly informed by 75.7% of the respondents and another 17.6% authorized a third party to reveal their condition.

In contrast with this willingness to reveal their HIV status, the highest levels of non-disclosure are to the communications media (85.9%), teachers (79.4%), to their clients (79.0%), government officials (74.4%), work colleagues (57.2%), community leaders (59.9%) and religious leaders (54.0%).

10. TREATMENT

69.4% of the respondents are taking antiretrovirals, with the highest percentage found in residents of Santo Domingo (77.7%); but at the same time these represent the group with the lowest level of access to treatment (82.3%, versus 93.5%, 91.5% and 90.0% in the Cibao, the Southeast and Southwest regions, respectively). This would suggest that the use of antiretrovirals is not entirely determined by the access and therefore, other factors such as their availability could be playing a role.

At the same time, in the last 12 months two out of five respondents (41.9%) have held productive discussions with health professionals and a similar percentage (39.6%) also did on issues relating to their sexual and reproductive health, emotional wellbeing and drug use, among others.

11. REPRODUCTION

Four out of every five people interviewed (79.3%) have children; three out of five (57.4%) know that some of their children are living with HIV. This phenomenon is more frequent in Santo Domingo, where 75.2% is aware of the situation, while in the Southeast a smaller percentage of people (9.7%) reports that one of their children or more are living with HIV.

At the same time more than half of the respondents (52.6%) have received counseling on their reproductive options; approximately one of every four (23.2%) has been advised by a health professional not to have more children; 11.3% reported being coerced by a health profession to be sterilized after learning their health condition, and one out of five (21.0%) was conditioned the access to antiretroviral treatment to taking some type of contraceptive measures.

12. PROBLEMS AND CHALLENGES

In terms of **testing and diagnoses**, the main problems perceived by the respondents are: a) the lack of pre and post test counseling (17.6%); b) lack of confidentiality (13.0%), c) process delays in providing test results (12.6%); d) fear of knowing the results (10.2%); e) existing problems in the access to tests so they should be free (7.0%) and f) lack of training of the health staff (5.0%).

With respect to **sharing their health status and confidentiality**, the outstanding problems and challenges in the study population are: a) rejection, stigma and discrimination (30.2%); b) the lack of discretion or confidentiality (14.2%); c) lack of training of the health staff (13.6%) and d) more information and education for the population to respect people living with HIV; society is not prepared (8.6%).

When addressing **antiretroviral treatment**, the main problems and challenges mentioned were: a) the access and availability of drugs, a better distribution nationwide (18.8%); b) side effects (16.7%); c) lack of adherence, flaws in adherence (8.1%); d) the fear of not obtaining drugs in the future, the risk of suspension in delivery (6.9%); e) the government must assume its responsibility, it should cover their cost (6.0%) y f) too many pills, many drugs, reduce the doses (5.3%).

Finally, when the issue of ***having children being a person living with HIV*** was addressed, the most important concerns and challenges mentioned were: a) that the child would be HIV positive (28.6%); b) people with this health condition should not have children(12.2%); c) the health of the mother is at risk (11.4%); d) the lack of information for the woman or the partner concerning the risks of pregnancy (9.2%) and e) that people have no information on the availability of drugs to prevent mother to child transmission (7.1 %).

CONCLUSIONS

The research results reveal elements which suggest that people living with HIV have lower socioeconomic conditions than the national average population. In addition to the deprivations caused by these unfavorable living conditions, other problems are added such as discrimination and particularly for women, who are often mistreated by their current or former partners. Added to the exclusion due to discrimination, people living with HIV face other problems such as the loss of social placement, and as result of the rejection experienced in their environment, a manifestation of self stigmatization.

A negative aspect due to stigma and discrimination is the low level of knowledge among people living with HIV about the two instruments that outline and guarantee their rights: The Universal Declaration on HIV/AIDS and the AIDS Law of the Dominican Republic. In the scenario of vulnerability to which people are exposed as a result of these factors, one of every four (23.1 %) had his/her rights violated at least once in the last 12 months, and in this group a mere 10% sought legal compensation for such offense.

Despite this negative environment, the involvement of the respondents in efforts needed to promote a change of attitude in the population towards people living with HIV would not seem to be sufficient.

People perceive problems and challenges with respect to testing and diagnoses, such as: the lack of pre and post test counseling; a lack of confidentiality; processing delays to provide test results; fear of the results, and others.

In terms of confidentiality associated with disclosure of their health status, the main concerns are: rejection, stigma and discrimination; the lack of discretion or confidentiality and the lack of training of the health staff (13.6%).

At the same time, the main concerns and challenges in terms of antiretroviral treatment are: those associated with the access and availability of drugs; a better distribution system at country level; side effects and lack of adherence.

And when the issue of child bearing is addressed, there seems to be a relative consensus among the respondents in terms of not having children when one is

HIV positive, as only 15.3% has a somewhat positive attitude towards child bearing with this health condition. The basic reasons given by the population opposed to against include: the risk of having a positive child; people living with HIV should not have children; pregnancy places the woman's health at risk; lack of information for women and/or their partners concerning the underlying risks of a pregnancy.

Reverting the situation exposed by the study involves changes at the level of people living with HIV, in an attempt to achieve a more active placement in initiatives that would allow increased influence on the validity of their rights; social changes to increase the level of respect and acceptance towards this population group, so they may enjoy a better social and living environment; and changes on how the Dominican State interacts with this population segment, so that it may assume its responsibility of guaranteeing the fundamental rights of these men and women as citizens of this nation.

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