

**A CULTURAL APPROACH TO
HIV/AIDS PREVENTION AND CARE**

UNESCO/UNAIDS RESEARCH PROJECT

DOMINICAN REPUBLIC'S EXPERIENCE

COUNTRY REPORT

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Introduction

The central objective of this study, which considers how a cultural approach can be taken to HIV/AIDS prevention with a view to sustainable development, is to try to take the measure of some of the main “lessons learnt” in the care and prevention of this disease in the Dominican Republic over recent years. The purpose of this attempt is to provide suggestions for measures that are tailored to the needs of the different groups of young people in the population, particularly the most deprived and disadvantaged, taking into account the social filter through which they perceive and understand the disease, their traditions, beliefs and convictions, and their attitudes and conduct. This report should provide new pointers for future action and priorities for research along cultural lines.

When UNESCO expressed an interest in conducting a study of this kind in the country, the National Council for the Study of AIDS (CONASIDA) and the local office of UNAIDS had just arranged with IEPD/PROFAMILIA to carry out a nationwide HIV/AIDS Situation and Response Analysis, including both documentary information and fieldwork, with emphasis on epidemiological and social science research and on the experience of numerous sections of society that had been affected by the AIDS crisis.

Accordingly, a team of researchers and consultants with expertise in dealing with HIV/AIDS on a cultural basis (demographers, epidemiologists, anthropologists, sociologists and social psychologists) joined together with HIV-positive individuals in this effort to reach out for an interdisciplinary understanding of the phenomenon. The objectives of this situation and response analysis largely reflected the UNESCO terms of reference for the cultural approach, and for this reason it was decided that the present study would be carried out as a *supplement* to the first, to avoid unnecessary duplication of effort. Many of the questions raised in the cultural approach are answered in the Situation and Response Analysis, so this report will indicate which parts are to be found in the sister study.

The objectives of this study were as follows:

1. To understand the interaction between cultures, the development of the HIV/AIDS crisis, and a number of development problems such as recession, environmental changes, poverty, urban/rural development, exclusion, gender and youth, tourism, migration, medical care, education and unemployment, among others (particular aspects such as tourism, migration, medical care and education are analysed in detail in the Situation and Response Analysis);
2. To identify cultural factors and resources (religious, spiritual and ethical values, taboos, family and power structures, gender roles and relationships, forms of sexual behaviour, machismo, monogamy and polygamy, perceptions of health and sickness, conceptions of life and death and of time and the future) that may be of importance in the spread, prevention and treatment of the epidemic;
3. To analyse the role of cultural factors and resources with a view to ensuring that the action taken is relevant and efficient;
4. To identify the needs of deprived groups and methods for dealing with them culturally;
5. To identify priorities for future research and strategy.

In order to achieve these objectives without duplicating the contents of the situation and response analysis, this study places emphasis on the cultural approach of the most deprived and disadvantaged groups among the young since, for socio-economic and cultural reasons, these have the most direct links both with the sex industry and with the HIV/AIDS epidemic. The people covered by the study were chosen specifically because their lives had been affected by HIV/AIDS, because they engaged in activities that put them at risk of infection, or because their profession, trade and/or adherence to sexual, social or "street" subcultures meant they lived with a high risk of infection.

The initial UNESCO proposal contained provision for measures and field research to form part of a possible participatory research-action programme. These would have included identifying community and religious leaders involved in HIV/AIDS prevention and recruiting them to participate in a programme of action. This did not form part of the study's objectives, however, as neither the time nor the funds were available.

The findings of this study should provide a basis for drawing up methodological proposals for using cultural approaches in the design, implementation, adaptation and evaluation of AIDS strategies and programmes, and for improving the skills and awareness of actors and agents in this field. The information that we have collected is to be used in conjunction with the results of the situation and response analysis in the next stage of the CONASIDA and UNAIDS strategy, which is strategic planning of a decentralized programme of HIV/AIDS prevention and control in our country. These two studies, then, should give rise to innovative programmes and projects and participatory processes aimed at promoting sustainable development, creating awareness and adapting strategies to the cultural approach.

The principles that guided the execution of this study were the following:

1. HIV/AIDS is a socio-economic and cultural phenomenon, related to other diseases, that interacts with structural conditions such as development problems, living conditions and cultural, hegemonic and marginal ideas, which means that an interdisciplinary approach is required to understand the real facts of the crisis and the impact it is having on the groups at highest risk of infection.
2. A long-term view is taken, with the cultural aspects of AIDS being considered in dynamic terms as constantly evolving, in the hope that a better future can be achieved by coordinated, sensitive measures that build on an understanding of these aspects.
3. The diversity of cultures must be respected, and participatory action must be based on flexibility and understanding, with appreciation of the steadfastness required to find common directions for sustained action.
4. The individuals and groups concerned must be encouraged to participate, and more particularly the young people from deprived sections of society who are associated with the self-support and mutual help groups now coming into being for people who live with HIV/AIDS. The field for participation includes the cultural accuracy of information, the design of the study, and the collection and analysis of data.

The common themes of this approach are:

1. The cultural and social impact of HIV/AIDS in the context of sustainable development;
2. Cultural characteristics and resources that have a powerful impact on the HIV/AIDS crisis and that need to be taken into account;
3. The roles of these characteristics and resources as obstacles or resources;
4. Identification of priority needs.

The situation and response analysis gathered information, some of it documentary (statements made by the country about the progress of the epidemic, epidemiological and social studies, the extension of prevention and detection work and medical treatment, current field research methods) and some of it collected in the field (interviews in medical, educational, legal and workplace settings, etc., cultural factors in the situation and incipient changes in cultural behaviour patterns). Analyses of successful cultural approaches and experiments were also carried out, particularly through the work of non-governmental organizations (NGOs) specializing in HIV/AIDS.

The bulk of the work involved in this inquiry into the cultural approach consisted of a series of semi-structured interviews with young people of both sexes aged from 15 to 24 and belonging to the most economically disadvantaged or deprived sections of society, these groups being considered highly vulnerable to HIV infection owing to the links of one kind or another that they have with the sex industry.

Above all, this study aims to add the requisite depth and breadth to the situation and response analysis by calling attention to the concerns articulated by the groups most affected by the HIV/AIDS crisis in the country. This cultural approach is based on what they had to tell, and it is only through the lives and struggles of these men and women that any sustainable development action relevant to AIDS can be undertaken.

Method

The design of the situation and response analysis fell into two basic stages. The first stage involved the collection and analysis of existing documents on normative aspects and plans for dealing with the epidemic. In the second stage, the various sources of information to be drawn upon for the study were selected. Evaluations, annual reports, design documents, research and evaluation reports, epidemiological monitoring reports and “current approaches” (National AIDS Plan, Field Research Plan and Women and AIDS Plan) were collected and analysed.

The documentary information, which was to be used for both studies, consisted of a bibliographical survey of research and publications relating to the HIV/AIDS epidemic in the Dominican Republic. Research was also carried out into institutions, both public and private, involved in the prevention and/or treatment of the disease. This yielded a total of 155 theses dealing in different ways with the issue of HIV/AIDS in the Dominican Republic.

Information was also sought on the ground. A survey was carried out among people living with HIV, groups and focus groups were interviewed, institutions were visited and structured and semi-structured interviews were carried out. The interviews and focus sessions were recorded, transcribed and summarized.

The ethnographic fieldwork carried out specifically for the cultural approach included a survey among a 59-strong sample of HIV-positive individuals. To this subpopulation was distributed a content questionnaire containing 32 questions that inquired into certain demographic and socio-economic aspects and into other aspects related to the situation of these people and their family and social interaction. Another 63 structured interviews were also carried out with people deemed to form part of the highest-impact population for the epidemic. These interviews included the following groups, in the age brackets shown:

1. “Bardajes” (transvestites) operating as sex workers (18-24).
2. Young homosexuals or “gays” (16-22).
3. Insertive male sex workers (“bugarrones”) (15-24).
4. Male sex workers (“sanky-pankies”) (18-24).
5. Controllers of female sex workers (pimps or “chulos”) (16-22).
6. Street boys (“palomos”) (17-18).
7. Policemen and soldiers (19-23).
8. Female sex workers in brothels (16-24).
9. Female sex workers on the street (16-24).
10. Shamans or folk healers (“curanderos”, “curiosos” or “facultos”).
11. Layers-out in undertakers’ establishments.
12. Burial workers in cemeteries.

13. Mothers of people who have died of AIDS.
14. HIV-positive wives of living HIV-positive men.
15. HIV-negative wives of living HIV-positive men.
16. HIV-negative husbands of living HIV-positive women.
17. Neighbours of HIV-positive people.
18. Members of a community with a high AIDS impact.

Lists of special questions were drawn up for interviewing these people. To ensure the responses would be comparable, a common list was prepared for the first nine groups, including personal data, sexual orientation and age of initiation, attitudes towards different forms of sexuality and sex work, perception of AIDS, the guidance on HIV/AIDS that they would give their children, and the story of the AIDS case that had had the greatest emotional effect on each respondent. Similar questions, tailored to the situation of each other subgroup, were put to the other participants. The questionnaires and lists of questions used for these groups can be found in the Appendix on Measurement Instruments.

To ensure anonymity, confidentiality and empathy with the participants in the cultural approach, members of the Network of People Living with HIV/AIDS (REDOVIH) were specially trained by the Research Team. These people collected the actual data on the ground, in the case of the survey and the interviews with HIV-positive people and their families and with the young people from deprived groups. They also took part in sessions to describe, analyse and discuss the results.

Results

The state of the epidemic in the circles where the adolescents and young people interviewed move is regarded among them as something quite alarming, "kept fairly quiet, but always there". The gays, the security force agents and the transvestites had known between two and twenty people with HIV or AIDS apiece, while the "bugarrones", "sanky-pankies", "pimps", "street boys" and female sex workers had known between one and four people in this condition. These data appear to reflect the state of the epidemic in these groups, as revealed by other sources in this analysis.

As will be seen later, other important findings came out of the interviews with adolescents and young people in these groups, in particular the tendency for sexual initiation and work in the sex industry to begin at an earlier and earlier age, the development of strictly gay (and not transvestite) sex work, the scantiness of the precautionary advice they would give their children, the attitudes of acceptance and rejection of homotropic and heterotropic female and male sex work they display, the importance of using condoms with customers to avoid infection, equivocality (in the best of cases) in the hypothetical treatment they would give to an infected partner, and the generally restrictive nature of the measures they would use to prevent and control the epidemic.

"Bardajes" or transvestites

The "bardajes" or transvestites interviewed had the highest level of awareness of the risk of HIV/AIDS of all the groups studied, perhaps because this is the group that has hitherto been most affected by the epidemic. They stated that they knew of some HIV-positive transvestites and customers who remained sexually active and concealed the infection, probably out of fear of stigmatization, discrimination, ostracism and marginalization.

Transvestites see sex work as part of their culture, in that it provides a way of generating a monetary income, even if this is scanty and hardly above subsistence level. Despite the impact of the epidemic and people's negative attitudes towards them, the demand for their sexual services has survived in one form or another. This makes it more difficult for them to consider relinquishing this work, when they cannot visualize rapid and viable alternatives to it within the Dominican sociocultural context.

Nonetheless, transvestites do not perceive HIV infection as inevitable, as they say that they all protect themselves by using condoms with customers, who themselves demand this protection to avoid becoming infected. They also say they are avoiding oral sex. More important still is the fact that they emphasize condom use with their lovers or steady partners, since they assume that these will have (unprotected) relationships outside the couple. It should be stressed that refusal by a customer (and probably by the transvestites themselves) to use a condom is regarded as a sign that the person concerned could have some sexually transmitted disease, including HIV.

Gays

The interviews with young gay men brought to light cases in which sexual initiation had taken place between the ages of 5 and 8. One such involved the oral rape of a child, who acknowledges that he was attracted even then by people of the same sex. According to local ideology, violence of this kind is supposed to be "provoked" by certain "effeminate mannerisms" of the child, while at the same time it confirms the social prophecy that he *is*

homosexual. In other words, this is a case where the victim is held responsible for the crime. This could explain how many young people who develop AIDS in adolescence or the early years of adulthood contracted the infection in childhood, being prevented from seeking help by the need to avoid giving away their condition.

Again, it is striking that two of the minors carried out sex work in discotheques and sex work districts as “gays”, but without wearing women’s clothes, as transvestites do, or adopting exaggeratedly masculine outfits or attitudes, as “bugarrones” do. This form of sex work among minors, which is something of a break with stereotyped gender roles, seems to be relatively new in Santo Domingo and merits more careful study because of its characteristics and its possible implications for the prevention of HIV transmission.

Some “gays” displayed worrying attitudes which suggested that they were persisting in forms of behaviour that carried a risk of infection: they said that they would tend not to use condoms if the person with whom they were going to have sexual relations was “trustworthy” or they “knew” them, if they had the AIDS test done, or if they did not ejaculate inside their bodies. These statements are evidence of poor understanding of how fallible the selection of a partner can be, of the role of preseminal liquid in intercourse, and of the risk of the immunological window in HIV testing. These aspects need to be emphasized in fieldwork strategies with these groups.

The minors appeared to establish less durable and committed partnerships than the adults, which meant that they neither expected fidelity from their companions nor neglected to use condoms with them. The adults, by contrast, expected fidelity from their partners, but realized that they could not control this, and consequently they also said they used condoms with their steady partners. In the event that a partner proved to be HIV-positive, the minors would tend to display attitudes of avoidance and vengeance, whereas it appeared that the adults were less inclined towards rejection and more likely to continue the relationship.

Insertive homotropic (same sex oriented) sex workers (“bugarrones”)

The “bugarrones” emphasized the need for condom protection as a necessary condition for carrying out sex work, which they regarded as a right, whether it was performed by men or women. They realized, though, that this activity was not highly regarded by the general public. Like the transvestites, the “bugarrones” said that they did not engage in oral sex and that they “would be safe” from AIDS if they always used condoms during sexual intercourse. One of them said that although “I don’t like it very much ... I have to do it”. Nonetheless, “if it’s a woman who’s one of us”, who supposedly does not go out with other men, they would not use a condom. If their partner turned out to be infected with HIV, their attitude would be one of resignation, and they would dose themselves “until my time comes”.

Heterotropic (opposite sex oriented) male sex workers (“sanky-pankies” and “controllers” or “pimps”)

On the subject of receiving money for sex from both women and men, the “sanky-pankies” showed more permissive attitudes, while the “controllers” emphasized what they saw as the value of the work in confirming their manliness, and expressed themselves in fairly homophobic terms concerning sexual relations between men. Like the transvestites and “bugarrones”, these two groups said that they avoided AIDS by using condoms. They believed that condoms were being used more now, although only one said that he used them with his woman (steady partner). If their partners turned out to be HIV-positive, the attitudes

they would display would be quite negative: they would abandon the partner and resign themselves “until death comes”.

Agents of the security forces (police and soldiers)

Regarding female sex work, the activities of gigolos and homosexual relationships, the opinions of the participants were divided, some for and some against. The same was true concerning possible changes in the sexual behaviour of the population. Some said that young people aged 13 to 25 took no care of themselves, while others claimed that sex was more selective now. Their preconditions for having sexual relations with another person were to “get to know one another first, use condoms, and go to the doctor for tests”. All four, however, rejected the idea of using a condom with their steady partner, “unless something is suspected” (an infidelity or a sexually transmitted disease). If their partners turned out to be HIV-positive, one of them would check “to see if I had it”, another would stay with his partner, a third “would convert to religion” and the fourth said he would kill her. They suggested “rounding up the street women, isolating the people affected and putting them in a home”.

Street boys (“palomos”) who are not sex workers

Like the transvestites, the street boys approved of female sex work subject to the condition that “they don’t go around making anyone ill”. There was no agreement on the subject of “living off women”, and they displayed strong homophobia, similar to that shown by the “controllers” and some security force agents. They believed that “a lot of people have dropped out of the ‘scene’” and that condoms were used a great deal. Personal hygiene and condom use were prerequisites for a sexual relationship, but if they had known the woman “for some time” they would not use condoms. With their steady partners they did not use condoms “because she’s my woman and I trust her”. All three said that if their partners turned out to be HIV-positive, they would kill them.

Female sex workers

Interviews were held with eight young women who carried out sex work. The results are summarized below. The four under-age sex workers were aged from 16 to 18. Those who worked in the street had had their sexual initiation between the ages of 9 and 11, those in the brothels between the ages of 14 and 15. They regarded the AIDS situation as “dangerous”, and said “a lot of people are dying”. They knew from one to four people with AIDS. The four adult sex workers were aged from 22 to 26, and had had their initiation between the ages of 11 and 17. They knew from two to four people who had died of AIDS. The women employed in brothels tended to hide the nature of the work they did from their families.

As regards what they would tell their male children about AIDS, the responses varied from persuasion and prevention (“trust me, protect yourself with a condom, take the test”) to restrictions that were inconsistent with their own work (“be careful of the street, don’t pick up street women”). They would give similar instructions to their daughters (“she should use a condom, protect herself properly, know how to look after herself, she shouldn’t let herself be taken in by promises, she should avoid the street, she should marry a man who’s for life”).

They tended to justify female sex work as a way of earning a living: “It’s not good, but I couldn’t finish my education.” The others said: “If I don’t work, nobody’s going to give it to me for free ... everyone gets by the best they can ... but you should take good care of

yourself". For a man to live off women, however, was relatively frowned upon: "I'm against it, because a man can work out there ... it's men that are supposed to give money to women ... they shouldn't be in society, because they're the ones they call pimps." Others, however, said that "they bring in money as well" and that "he should put a condom on and always protect himself". To a man who "did it" with another man they would say "don't do it, it's a bad thing to do ... men weren't made to do it with other men, but with women", although they realized that "there are a lot who do it because they like it ... there are some who are 'born to it' while others aren't. I don't criticize that".

On the subject of changes in sexual behaviour, they said that men "go out less" and that previously customers had done it without protection, but that now most of them used a condom, or masturbated while carrying out oral sex. Some were fearful, others were not. When having sexual intercourse with customers the women insisted on condoms and refused to deep kiss, although some "do it without a condom". Some always used condoms with customers, but not with their husbands (steady partners). Others believed it was better to use condoms in all cases "because he might have other girls", "nobody knows what he gets up to out there" and "I don't trust anybody".

They were asked what they thought they would do if their partner had AIDS. Two would simply take the HIV test to see if they were infected, three said they would leave him or kill him and themselves, and three would reconcile themselves to it, accept it and support him. They thought the Public Health authorities should help the street boys and women sex workers, carry out HIV testing in the brothels and set up aparthotel type care centres for people with AIDS where their families could visit them.

Case studies of people who are HIV-positive or have AIDS

Every one of the young people interviewed, of both sexes, came out spontaneously with the story of the AIDS case with which they had been most closely involved. These cases included brothers, friends as close as brothers, best friends, distant friends and acquaintances, work colleagues and neighbours. Fifteen of the cases were male and fifteen female. The gender of the cases chosen did not vary according to the gender of the respondents.

The male cases included one transvestite, two "gays" (one of them a user of intravenous drugs in the Dominican Republic), four bisexuals (one of them the husband of a sex worker and two of them "bugarrones"), one exclusively homotropic sex worker (no relations with women), another man who was the husband of a sex worker, a brother who lived abroad, two friends (perhaps customers, presumably heterosexual), two neighbours who were small traders, and a "street boy".

The female cases included nine sex workers (four of them serving tourists, while two of them were the wives of men who had died of AIDS), one woman who made business trips abroad, one professional, two housewives, one free-trade zone worker, and one domestic worker.

Twenty-five of the 30 had died, which gives a dramatically high mortality rate (83%). In 21 of the cases, the families had tried to conceal the infection, in one case even from the person actually infected, or had told the neighbours that it was some other, less stigmatizing disease. This almost always happened at the beginning of the illness, until the signs and symptoms became self-evident, since, as they put it, "it was going to come out sooner or later". In some cases the families did not reveal that the person had had AIDS until after their

death. Five of the families had made the condition of the individual public, although not always with the best of intentions.

In the 15 male cases, 12 received some family support, 10 received support from some friends and eight received support from neighbours. In the female cases, 10 received some family support, nine received support from some friends and 10 received support from neighbours. As can be seen, there appears to be a slight tendency for men living with HIV/AIDS to get slightly better treatment from society than women in the same condition.

An analysis was carried out to ascertain which people were most accepted or rejected at the three levels referred to above. For this purpose, scores of 0 (most negative) to 3 (most positive) were allocated to each type of response, depending on its quality, giving a final scale from 0 to 9 points.

The best treated of all (6 to 7 points) were three men and one woman, namely: (1) a 35-year-old man, deceased, bisexual, the husband of an HIV-positive sex worker who travelled abroad, and who presumably infected him. His friends said that once they knew he had the illness they treated him better than before, perhaps because they regarded him as a victim. He was followed, with 6 points apiece, by: (1) a 27-year-old man, married with children, who came back to die from New York, and whom the neighbours helped to take baths; (2) another 27-year-old man, a sex worker with four children, whose neighbours were very distressed; and (3) a woman aged 26-32, now dead, who was a sex worker and mother of an HIV-negative daughter, and who was "very kind and sincere, and made everybody fond of her".

The worst treated (0 points) was a 30-year-old woman, a tourist sex worker who operated on a beach in the country. She was followed (with 2 points apiece) by six men and five women: (1) a 17-year-old transvestite, who was expelled from his home, and whose friends were held to blame for his homosexuality and illness; (2) a 16-year-old bisexual sex worker, whom the neighbours ridiculed; (3) a 23-year-old "controller" or pimp, the husband of a sex worker who had left him, and whose small daughter the neighbours mocked because of her father's illness; (4) a 30-year-old man with two children, whose neighbours refused to touch him; (5) a 33-year-old professional, whose friends broke off all contact with him; (6) a small trader who was deserted by his customers.

The same score was received by: (7) a 16-year-old street sex worker who was abandoned in a park, spurned by her work companions and helped only by street boys; (8) a 22-year-old street sex worker, whose husband had died of AIDS; (9) a 35 to 38-year-old sex worker in a brothel, with two children, who was dismissed from her job and spurned by friends and workmates; (10) a 27-year-old housewife whose young child died of AIDS one week after its mother, whereupon the neighbours raised a collection for the burial; and (11) a 23-year-old woman whose family moved out of the neighbourhood after accusing a neighbour of AIDS-related witchcraft and having her arrested.

Cases experienced by adolescents and young people from deprived groups

Every one of the young people interviewed, of both sexes, came out spontaneously with the story of the AIDS case that they had been most closely involved with. The mortality rate of these cases was dramatically high (83%). Most of the families had tried to conceal the infection, usually in vain. This attitude was generally frowned upon by neighbours. The diagnosis of HIV was perceived and experienced by almost everybody as meaning that death was imminent.

In most cases, some support was received from family, friends and neighbours, despite the financial straits in which most of the households and communities concerned found themselves. Men and women played different roles in caring for and supporting the sufferer. There was a slight tendency for men to receive better treatment from society than women, although this depended more on the individual's lifestyle, personality and conduct. The children of HIV-positive individuals were not discriminated against by other children or their parents in the community.

Individuals and families directly affected by HIV/AIDS

The data from the interviews showed that couples revealed their condition to their families, friends and neighbours more often when both of them were HIV-positive than when only one of them was. In the latter case, the couples concerned had hidden the infection from the woman's family, and from most of their friends and neighbours, when the husband was infected. When the husband was negative, only the woman's family and friends knew about her infection. The mothers of HIV-positive individuals who had died had revealed the condition of their children to their friends and neighbours and received solidarity and support from many of them, despite general poverty. Women cared for the sufferers and did housework, while men helped to transport them from place to place and provided money.

People living with HIV/AIDS

Men and women living with HIV/AIDS were interviewed in support groups, health centres and churches. The two sexes tended to react differently to the news of the diagnosis, which produced resignation in men and panic and depression in women. In many cases, there was evidence of families reacting to the diagnosis of HIV infection with apathy and rejection. The fear of rejection, stigmatization and other adverse reactions appeared to be what led people to conceal the illness.

The difficult financial circumstances of many sufferers, combined with the unemployment which almost always ensued as soon as the symptoms of the illness began to appear, made it difficult to obtain essential food and medicines. Only a tiny minority had access to antiviral medicines. Discrimination ran along class and generational lines. Participants with less schooling were marginalized and discriminated against more than those who were more highly educated. The youngest were the most discriminated against by their families and communities, and the oldest by the health services.

Only one in five did not belong to groups of HIV-positive people, although this is not representative of the HIV-positive population in general. Despite the great financial constraints under which self-support and self-help groups operate, membership of these appears to be essential if people are to receive a basic education about AIDS, a minimum of emotional support and at least the essentials of medical care and supervision, as well as access to medicines.

People indirectly affected by AIDS

Of the shamans (folk healers) interviewed, those who showed the greatest experience in dealing with HIV-positive people said that they knew they could not cure the illness, and that they did not expect anyone to think they could. They felt that their task was to "calm down" sufferers emotionally, providing them with support, advice, and greater serenity and composure. They had prescribed herbal plants such as *uña de gato*, a concoction known as

agua de la buena suerte, natural products, potions and lime tea, a natural relaxant. Layers-out in undertakers' establishments wore a gown, gloves and mask as a safety precaution. They did not feel that preparing an AIDS victim was anything out of the ordinary. Burial workers in cemeteries did not take any special safety measures. However, magical beliefs about infection apparently persisted with them, as they refused to carry the coffins of the deceased and insisted that they had to be covered with particular care.

High-impact community

In the last three years, public talk and the media have identified a *batey* (sugar-growing colony) in the National District as a place with a high number of AIDS cases. Key respondents agreed that there was fear of AIDS in the community. However, there had been only three confirmed cases, dating from two years previously. Each residential area had a neighbourhood council, and women's and youth associations were in operation, but "everyone is working on their own" as regards prevention.

Discussion

In this section we shall concentrate on the information collected through interviews with people whose lives have been affected by HIV/AIDS, people who engage in activities that place them at risk of infection, and people whose profession, trade and/or association with sexual, social or "street" subcultures mean that they live at high risk of infection. This section will be organized in accordance with the following objectives, which are set forth in schematic form in the introduction to this report:

1. A comprehensive understanding of socio-economic and cultural interaction in the development of the HIV/AIDS crisis. Specific attention will be paid to the impact of urban economic development and the importance of the sex work industry within the informal economy as an economic survival option for a large proportion of women and young people in deprived communities.
2. Resources and cultural factors related to the spread and prevention of HIV, with emphasis on ideas of fidelity, sexual behaviour, monogamy/polygamy, gender relations, religious, spiritual and ethical values, machismo, hegemonic perceptions of health, sickness, normality and family power structures.
3. The role of cultural resources and factors in ensuring the relevance of institutional measures.
4. The needs expressed by disadvantaged groups affected by the HIV/AIDS epidemic and methods of prevention and assistance that are sensitive to the impact of culture on the development of the epidemic.
5. Basic priorities for future action and research strategies, which must be sustainable, sensitive and respectful.

Objective 1. The AIDS crisis, sex work and the informal economy

This section contains a critical analysis of the socio-economic and cultural structures that impact the experience of the HIV/AIDS epidemic in deprived Dominican communities. In accordance with the first objective set by UNESCO, this cultural approach begins with an analysis of the Dominican informal economy.

According to a number of sources, such as the Economy and Development Foundation and the Caribbean Economic Research Centre, between 40% and 60% of Dominicans live in poverty. Only an estimated 8.3% of the Dominican population have incomes of more than 6,000 pesos a month, while some 43% of the population have monthly incomes of no more than 1,500 pesos (ENDESA-96). Average monthly outgoings per family are DR \$1,151.75 (US \$1.00 = DR \$15.5) (Central Bank of the Dominican Republic, 1998).

These figures, and particularly the discrepancy between the incomes of most Dominicans and the cost of living, provide conclusive proof of the key role played by the informal economy in enabling most of the population to survive. At the same time, they are indicative of the variety of services that are needed to keep so many Dominicans informally "employed". The range of occupations and services in the Dominican informal economy includes a wide variety of street sellers (who hawk everything from fruit to mobile phone chargers), unregistered businesses, public sector employees who "speed up" services for extra payment, and the large sex work industry, among others.

As in other underdeveloped countries, the Dominican informal economy centres on urban and periurban areas, where a high percentage of the population lives, the figure being put at over 56% by the 1993 Population and Housing Census. In the urban centres of the Dominican Republic, the informal economy both competes with and complements the institutions and structures of the formal economy.

A vital part of the informal economy, and the most prominent link between this and the current HIV/AIDS crisis in the Dominican Republic, is the sex work industry. Although it is difficult to put a figure on the actual percentages of people doing sex work, a number of studies that have been carried out suggest that at least 10% of Dominican women, most of them aged between 15 and 24, do sex work to survive. In *bateyes*¹, the percentage of women carrying out sex work stands at between 10% and 15% of the female population (Capellán, 1992). The real numbers of women performing this work are higher than these estimates, as they do not include the more elusive numbers of women hired by cafes, bars and brothels in urban, tourist and industrial areas as waitresses and companions rather than as sex workers.

Estimating the percentage of Dominican men that carry out sex work is an even more difficult feat. The powerful social stigma against homosexuality in predominantly patriarchal societies means that sexual relations between men are not discussed in public. The stigma against homosexuality, which is popularly perceived as the receptive role in anal intercourse between two men, partly derives from the perception that this role is feminine, weak and powerless. These characteristics are popularly regarded as being in opposition to those possessed by the self-styled “normal” and respectable patriarchal male (De Moya *et al.*, 1995).

Despite the silence imposed by the prevailing prejudice against male sex work, in the Dominican Republic there is a steady demand for young men for the purposes of anonymous casual sex. In virtually every socio-economic class, furthermore, a cult status is given to virginity. This is illustrated not just by the preference for under-age virgins in casual sexual relations, but also by popular cultural notions which suggest, for example, that intercourse with a virgin woman can cure sexually transmitted diseases.

Although the figures are elusive, it has been found in districts of Santo Domingo that some 28% of lower-class men aged between 17 and 28 and 17% of middle-class men between the same ages have had some sexual relationship with another man in their life. Of these, around half admit to having carried out this (insertive) act for money (Frías and Lara, 1987).

It should be noted that although the figures show sex work to be a large, established industry within the informal economy, there is little tolerance towards sex workers in the cultural ideas of morality and sexuality that prevail in Dominican society (García and Renshaw, 1987). The stigma associated with effeminacy in pre-adolescent and adolescent males in general, accentuated by the fact of their working in the sex industry, means that these are constantly having to prove their masculinity to one another. By means of activities and language associated with manliness, these youths seek to show that they are not “kids” and that when they grow up they will be “tigers” – dominant males – and “street-wise”.

¹ *Bateyes* are very low-income agricultural communities that grow sugar cane. Most of the people living in *bateyes* are male cane-cutters.

Paradoxically, one of the main practices whereby young sex workers establish that they are not “gay” (even though they have sexual relations with men for payment) is to “sodomize” another young sex worker, whence the phrase “tigre-rapa-tigre”, literally “a tiger preying on a tiger”, which establishes beyond dispute the heterosexuality (as demonstrated by sexual violence) of the young sex worker, while at the same time revealing the basis of economic survival that underlies the sexual “transgressions” of young men who go “looking for it” on the street (De Moya and García, 1998).

The prevalence of sex work in urban and periurban communities with a low economic level and in industrial and commercial areas, where the informal economy flourishes, is indicative of the viability and predominance of this occupation as an economic option for a large segment of the population, especially women with young children whose husbands have left them. Although it is stigmatized and scorned by hegemonic views of morality, work and sexuality, sex work continues to be “the best option” for many people who are on the periphery of the socio-economic structure. Prominent among them are women and young people of both sexes with few resources and little schooling.

It needs to be recognized that, as well as centring on urban and industrial areas, informal sex work predominates in the tourist areas of the country, whether it is carried on by street or beach sex workers, “sanky-pankies”, “bugarrones”, under-age youths or hotel employees, and it is in these areas that the highest rates of HIV/AIDS are found.²

The predominance of sex work done by women is due in part to the oppressive structural situation (economic vulnerability and a lack of education and “better” options) that affects a high percentage of Dominican women, 25% of whom are single mothers (ENDESA-96). The predominance of this type of work is also linked to the cultural notion that it is “right and proper” to reward women financially for making their sexual attributes available for pleasure or payment. In the context of the cultural patterns of Dominican society, it is generally held that women’s sexuality is a source of income of which they have the right to take advantage, a conception that is represented metaphorically in colloquial speech as a “fertile plot”, like the smallholdings worked by Dominican peasants to provide for their survival.

A number of HIV/AIDS prevention programmes have turned the concept to account and have included slogans such as “Take care of your plot”, exhorting women to look after their sexual health, in their women’s education campaigns. This type of cultural integration and awareness work has helped spread important HIV/AIDS and STD prevention messages and basic education about sexual health, in language that is accessible to most of the population.

Despite the apparent general decline in HIV infection rates among women sex workers, the incidence of infection among them is still between 5% and 10%, depending on which community is being studied. This is a strikingly high figure. The highest indices of seropositivity are among people with few economic resources, many of whom carry out sex work. The prevalence of HIV/AIDS within the complicated and fluid structure of economic survival and sexual subcultures in the Dominican Republic shows that these women are a fertile “plot” for the epidemic.

² The “HIV/AIDS Situation and Response Analysis” that accompanies this report includes additional information on the prevalence of HIV/AIDS in tourist areas associated with sex work.

In the sex work industry, economic factors such as occupational risk, a lack of negotiating power among certain groups of sex workers and the economic desperation that results from the insecurity and instability of disadvantaged workers' incomes, combined with cultural aspects relating to sexual behaviour, fidelity and the danger of infection, mean that the HIV crisis is having a different impact on different subgroups within the industry.

The effect of this combination of factors is illustrated by the high rate of HIV infection among transvestites, whose 34% HIV-positivity rate means that, together with young men who identify themselves as "gay" (11%) and women street sex workers (around 9% in urban areas of the National District), they head the list of the subgroups most affected by the epidemic within the sex work industry. These three subgroups have a number of structural aspects in common, including the preponderance among them of deprived youths who live on the streets or in very poor areas, the economic independence from their families which is a characteristic of these youths, of both sexes, and the social stigma against their profession created by dominant views of sexuality and work (which they themselves often adopt in the way they regard themselves).

Besides these structural aspects, another feature common to these three risk groups is that they play a predominantly receptive role in penetrative sexual relations for payment and pleasure. Certain popular beliefs hold that this role, which is mainly seen as feminine and passive, does not carry a risk of HIV infection. Thus, a significant number of the young sex workers interviewed in a study carried out in the Dominican Republic, particularly those who were both recipients and penetrators in male anal sex, believed that condom use was a necessary precaution when they were the penetrators in the sex act, but that it was *not necessary* when they were the *recipients* of anal sex.

According to these sex workers, the penis "absorbs" HIV through a "gap" which they believe is produced at the moment of ejaculation (De Moya and García, 1998). As a result, the belief is that condom use is only necessary for their *own* protection during the insertive role, but is *not* necessary when they adopt the receptive role and *another* person adopts the penetrating role. It would be superfluous to emphasize the high risk of infection run by young men who adopt this kind of behaviour.

Along with this kind of faulty information about how HIV is transmitted, there is a marked difference in "sexual negotiating power" between workers who adopt insertive roles and those who adopt receptive or "feminine" ones. The machismo and patriarchal authority that characterize Dominican culture remain operative when paid sex is at issue. "Bugarrones" and "sanky-pankies" maintain a heterosexual identity because of their almost exclusively insertive role and their participation in subcultures of sexual violence, and because they adopt a role that is masculine, aggressive and dominant in sexual relationships. Conversely, transvestites, gays and women sex workers are effectively deprived of the power of negotiation and sexual control because they play a passive and "voiceless" role in the sex act. Consequently, not only are these groups economically and socially marginalized to start with, but they have less of a "say" and less control in negotiations over methods of protection in the sexual practices that are their trade.

Given the high incidence of HIV-positivity among groups of sex workers who are mainly receptive, it is vital for education campaigns to include programmes that address the disparities in sexual negotiating power between insertive and receptive male sex workers and between female sex workers and customers. At the same time, these programmes need to include assistance agendas that take account of the important economic role of the sex work

industry as part of the informal economy in relation to the general economic situation, and that take a realistic view of the economic options open to deprived youths, women with low earnings (especially single mothers) and representatives of sexual subcultures in the Dominican economy.

In exploring the intricate ties that bind together the structural and sociocultural situations of people whose occupation, gender, age and socio-economic status place them in communities and groups at a higher risk of infection, we began to discern the main areas through which culturally sensitive and economically sustainable prevention, education and assistance programmes need to be channelled.

It is vital, however, to emphasize what is common knowledge, namely, that HIV/AIDS is not just confined within the socio-economic and cultural limits of the sex industry or the informal economy, and that a large number of cases of infection occur among stable heterosexual couples, when one of the partners is infected through casual unprotected sex before or after entering the stable relationship. Casual heterosexual relationships between single young men and women also lead to a high percentage of infection.³

Among the cultural ideas that inform predominant attitudes to sex and that, operating in conjunction with structural conditions, largely determine the collective code of social conduct in the Dominican Republic, is the notion of fidelity, or sexual loyalty. Although most Dominicans in stable sexual relationships expect and demand faithfulness from their partners, it is generally perceived as a “truth” that many Dominicans (especially men) are not faithful, and that anyone can have “their bit on the side” in the street.

In accordance with the requirements of the second objective of the cultural approach, the next section explores the impact that the expectation of fidelity has on frank discussion of sexual behaviour in Dominican couples, and on the current selective (and negative) use of condoms as a method for preventing HIV/AIDS.

Objectives 2 and 3. Cultural resources and factors. Their connection with the HIV/AIDS crisis and their role in ensuring that action is relevant and efficient.

Ideas about fidelity and condom use

One important finding, although it was already known, concerns what may be termed the “dilemma of condom use”. In general, and with the exception of the transvestites, the groups interviewed showed considerable resistance to the idea of using condoms with people they regarded as being “one of them” (“known”, “trustworthy”, “strict”, those who have themselves tested for HIV, steady partners and lovers, and women not taken to be sex workers), because they calculated that they were not at risk of infection from them. With other people who are regarded as being “from the streets”, the norm now seems to be to abstain from sexual relations, or always to use a condom if they are entered into.

This is probably due to the clash between the conception of fidelity and trust as being among the most important values for the maintenance of a steady relationship, and the frequent practice of having “one-night stands” outside the couple, mainly in the case of men, but among women too. Men and women who have been genuinely faithful to their partners hope that these will do the same in return, so that asking them to use a condom would be

³ The “HIV/AIDS Situation and Response Analysis” gives infection rates for these and other demographic groups.

tantamount to introducing an element of suspicion, or accusing them of having been unfaithful and/or of being ill. Consequently, it is found in some studies that women ask their husbands, whom they “mustn’t suspect”, to use a condom “to avoid getting pregnant”. By contrast, men say they use them to “avoid AIDS or an STD”.

The dynamic of these gender mechanisms – and sexual preferences – as they relate to the use of condoms in a stable relationship is complicated, and must not be overlooked. For example, it would be difficult for a heterosexual man to insist on using a condom with his wife, even on the excuse of preventing pregnancy, without jeopardizing his sense of manhood. Nor could his wife insist that he use a condom as protection against AIDS or an STD without it looking as though she were accusing him of being unfaithful or else incriminating herself. Her situation becomes particularly difficult if she has access to other methods of birth control that do not prevent the transmission of HIV or other STDs. Men and women practising insertive or receptive anal sex cannot draw on the argument of avoiding pregnancy. As a result, when they have to “give explanations” for condom use, they are forced to refer to the matter of preventing disease and the questions about infidelity that this raises.

Men and women who have not been altogether faithful, or those who do not want their infidelity to become known, feel that asking their steady partners to use a condom is equivalent to incriminating themselves or testifying to having been unfaithful and/or being ill, which makes it difficult even to suggest this. Consequently, many men say that they use or would use condoms (with other women), but not with “their” woman. In other words, “infidelity” consists in wanting to use a condom with one’s “legitimate” partner and not to use it with “illegitimate” partners.

By social definition, then, condoms appear to be used negatively, to protect oneself from the “other”, to avoid possible infections that could be passed on by occasional partners with whom there is no affective commitment, and of whose sexual exclusivity or state of health one cannot be sure. In a way, condoms act as a “psychological barrier” to potentially risky contact, and thus substantially reduce what is called “promiscuity”. Condoms are not used positively to protect the “other” person, i.e. the partners (whether faithful or not) to whom a sexually transmitted disease or HIV could be passed on, because the possibility that one could oneself be the infected person is denied.

Thus, the “negativity” of condom use can also be viewed, in part, as a result of the idea of selfishness. People who insist on using them frequently are seen as being intent on their own protection. It is important to note that there is also an accusatory aspect in this: someone who demands protection *from their partner* can be seen as implying, directly or indirectly, that their partner has been unfaithful. If someone insists on using a condom for the purpose of protecting their partner, this likewise raises suspicions about the behaviour of the person insisting on condom use.

In any of these cases, it is important to recognize the moral issue of “knowing” one’s steady partner, something that weighs heavily on the practical question of condom use. This was cited by virtually all those interviewed as a necessary condition, and sometimes a sufficient one, for unprotected sex. The respondents repeatedly stated that using a condom, or suggesting it, was inconsistent with their relationship with a “known” partner. The three street boys emphasized that they did not use condoms with their partners, “because she’s my woman ... if she’s my wife ... there’s trust”. Furthermore, the four security force agents, whose position as people who cross the street/home divide underlines their importance as

potential carriers of the epidemic, rejected the idea of using condoms with their steady partners “unless something is suspected”.

As these statements make clear, condoms are often viewed more as objects of suspicion than as a means of protection. Their associations with infidelity, with loose sexual mores, with sexual acts between people who are not (sufficiently) “known” and with people “from the streets”, as opposed to “our own people”, contribute to a negative perception of condom use, in which the moral image that is desired acts as a major obstacle to informed decisions about sexual health. As long as condom distribution and use are viewed through the prism of fidelity, this “image problem” of condoms is unlikely to change.

The different attitude that the transvestites had towards condom use is worthy of mention. Most of the respondents said that they would become involved in unprotected sex if they (a) knew the person, and/or (b) knew that the person was HIV-negative from the results of a blood test. Perhaps because of the nature of their more “intimate” and almost universal association with the high-risk activities of sex work and receptive anal sex, and because of their high rate of infection, the transvestites took a more “pragmatic” position on the question of fidelity and condom use.

“It’s different now, we transvestites all use condoms,” stated one of them, while another added, “I always use them, because just as I do it with my boyfriend, I’ll do it with someone else.” A third said, “Much as I love him and adore him, I don’t think anyone’s faithful in this world.” “You don’t know what he’s up to out there on the streets,” noted a fourth, referring to the almost omnipotent “street/home” divide, but at the same time drawing attention to the indispensable nature of this divide. In other words, this “bardaje” was drawing (as did almost all the other respondents in the other groups) on a well-established system of cultural judgement that divides the activities and people of the street from the activities and people of the home, but recognizes the difficulty that the inflexibility of this system raises. Most of the “bardajes” (and probably most human beings) are both “of the streets” and “of the home”.

Nonetheless, these pragmatic, unidealized notions of fidelity were the exception, not the rule, among the groups studied. By virtue of the way they deployed their sexuality, transvestites seemed to open up to their partners almost totally, and in some cases totally, about their sexual habits and histories. But this openness, which provided the basis for the decisions of respondents from all the groups studied as to whether to have unprotected sex with their partners, was not examined by everyone as critically as it was by the transvestites.

Notwithstanding the concerns expressed by other groups (female sex workers, “bugarrones”, gays, etc.), none of the groups stated as vehemently as the transvestites did that they would insist on the use of a condom with their steady partner. We might speculate that rather than being a virtue of the transvestites, this pragmatism is regarded by them as a necessity, as they have the highest rate of HIV-positivity of any demographic group in Santo Domingo. Although the insistence that a condom be used with all partners is admirable, the route that was followed to get to that stage – i.e. a high rate of infection – is certainly not one that other demographic groups at risk would wish to follow.

Linguistic hiatus: avoiding the reality of AIDS by using the word ‘it’

Many of the respondents evinced an almost ritualistic reluctance to use the words “HIV” and “AIDS”. This phenomenon, which was observed in the great majority of the

respondents, is a linguistic hiatus. It is as though giving a name to the epidemic and talking about it would not only give recognition to it, but enable it to enter their lives as an inevitable reality. Examples of this phenomenon can be seen in the following extracts from their accounts: “It’s terrible, just thinking about *it* brings me out in gooseflesh and makes me feel ill”; “*It* is like a punishment from God”; “*It* is a monster, it destroys, it changes people”; “*It* can only be caught by transmission through the man’s blood or semen”; and, lastly, “I talk [to my daughter] about her schoolwork, I never talk about *it*”.

This last extract is perhaps the most illustrative of this profound desire to avoid articulating the words “HIV” and “AIDS” and the social impact doing so produces, as it reveals the lack of dialogue between parents and children about the reality of HIV/AIDS. While many of the respondents, when asked whether they talked about the subject with their children, replied that they would ask their sons to use a condom and their daughters to be very careful in their choice of partners, none of them spoke of the need to discuss AIDS in depth with their children. On the contrary, the respondent just quoted, by using the linguistic hiatus referred to here, was glossing over the subject of HIV/AIDS with her daughter in what is actually a misleading way. All those who avoided articulating the word AIDS were trying, by means of their silence, to suspend the possibility of its becoming a tangible reality in their lives.

The need that these respondents had to exclude AIDS from their lives was perhaps symptomatic of how close they were to what they were trying to avoid, since all of them told the stories of people close to them who had died of AIDS or who were HIV-positive and managed to carry on concealing the disease, with great difficulty.

At first sight, it seems singularly paradoxical that people belonging to groups at risk of infection should shy away from the words “HIV” and “AIDS” and be so reluctant to discuss the matter with their families. One possible explanation for this mystery may derive from the “duality” of the social positions occupied by people who have made “the streets” their “workplace”, where they do their “job”, and not their “home”. Many female sex workers and “bugarrones” who “work” on the streets also have a “home” where they can take on roles that are more established and more accepted by society, and here they adopt “normal” or established attitudes towards family discussion of HIV/AIDS. People who “transgress” against social standards (of gender, sexual conduct and where and how to live) and thus do not experience this duality in their social position tend to be more willing to discuss the epidemic directly and frankly. Thus, those identifying themselves as “transvestites”, whose “sexual transgression” means they do not have the opportunity to adopt a “normal” lifestyle in their “homes”, tend to have a clearer view of the risk they run and of the need to discuss the epidemic and avoid glossing over it.

Concealing HIV infection

The linguistic hiatus that was a characteristic feature of the stories about HIV/AIDS recounted by the respondents was also a feature of the way the families of HIV/AIDS sufferers dealt with the presence of the epidemic in their families. Many respondents, when recounting cases in which close friends had contracted AIDS, observed that the families of these people invariably tried to conceal the identity of the illness against which their loved ones were battling. It is important to note that almost all those interviewed condemned this concealment of the disease.

“[The family] didn’t want to let on, they hid it for a time. That’s very bad, because she carried on sleeping with a lot of people after knowing she had AIDS.”

“Her relatives took her in and supported her, but they were ashamed. They said she had a brain tumour.”

“We fooled [him] by lying, we told him it wasn’t AIDS. That was a bad thing to do.”

“[The family] didn’t say anything at first, they didn’t alert the neighbours.”

“They concealed it, because they didn’t think everyone should know about it. It’s a family problem. He told me in confidence.”

“The family ... didn’t let on that it was AIDS, they said she had anaemia. That was really bad. I talked to some boys and to a neighbour, they said that she was thin, that she looked very odd, that she looked as if she had AIDS.”

“They didn’t let on that it was AIDS. They never let on, but sooner or later it is going to come out.”

Beyond saying that “sooner or later it [was] going to come out”, very few respondents gave concrete reasons for their disapproval of the tendency of families to conceal the presence of AIDS in their lives. In one case, one of the respondents referred to the “danger” represented by an HIV-positive person (without symptoms), as they might remain sexually active, and thus be an active agent of transmission. This attitude is indicative of the disruption of social behaviour and interactions caused by an asymptomatic HIV-positive state. For many people, someone who is HIV-positive, without symptoms, ceases to be a social entity; in other words, they stop being a *complete* person, enmeshed in a range of social interactions, and are “emptied” of their social content and characterized, in a singular and crushing way, by the fact that they are an HIV carrier. For most communities, an HIV-positive person who has not shown symptoms of AIDS, or has not taken the HIV test, or has not revealed its results, represents a real and frightening threat.

Given the stigmas and taboos that surround the revelation that one is HIV-positive, removing any possibility that HIV-positive people might live a normal life, there is a strong incentive for both families and individuals to conceal a positive state, and it often happens, whence the somewhat paranoid (but justified) observation made by many respondents that AIDS “can’t be seen in someone’s face”.

What is more, as the phrase “sooner or later it’s going to come out” indicates, there is a perception that the silence surrounding and “masking” an HIV-infected person shows a lack of frankness. In communities at risk, the fact that the infection “can’t be seen” creates a feeling of fear and of being uninformed, which argues against the practice of not revealing HIV infection but, ironically, provides an incentive for it. Something that it is vital to note, and that captures the complexity of the actual HIV/AIDS awareness and exposure of many people, is that by introducing a linguistic hiatus, a concerted effort to gloss over and neutralize the name of this disease, they are clearly revealing that they have been exposed to it. The self-same defence mechanisms that are used to deny the reality of AIDS make it clear that these people have been exposed to it in the past.

Thus, many respondents explained that they “protect themselves against it”. In other words, they accepted that they had no choice but to guard against this “evil”, and one of the

ways of doing this, apart from the more practical use of condoms, is to deny its existence by *suspending* its official name.

By and large, the respondents spoke favourably of families that had revealed HIV infection to their communities:

“Her relatives were stunned, because they weren’t expecting it. The family didn’t hide it, they haven’t turned their backs on her. I think that’s a good way to react. She said ‘I’ve got AIDS’.”

“When she was ill, her relatives treated her well, they didn’t turn their backs on her. That’s good. They didn’t hide it, they were completely open.”

It is important to note the approval that greets these instances of HIV infections being revealed, which is almost always expressed in conjunction with the favourable treatment that the infected person received from their family. It is as if, for those interviewed, the revelation of a positive state not only provided a feeling of security (enabling them to distance themselves from or change the way they interacted with someone who was infected but not showing symptoms), but also brought out a desire to care for and help the person when they were in the syndromic stage of the illness.

The acknowledgement of HIV infection and the visibility of the symptoms play an important role in the establishment of family and community support and care networks for people infected with HIV. Nonetheless, as long as HIV/AIDS continues to have a stigma attached to it (a stigma of which linguistic hiatuses and concealment of the disease are both symptomatic and productive), these support networks, which are so crucial given the current lack of sustained government support and action, will remain in jeopardy.

“Frontier” groups

Among the respondents interviewed, five groups in particular – the “bugarrones”, the “sanky-pankies”, the “pimps”, the street boys (“palomos”) and the security force agents – merit special attention owing to their “frontier” roles in high-risk activities and forms of behaviour while they simultaneously adopt a “normal” identity. As De Moya and García (1998) have noted, “bugarrones”, or insertive sex workers, while their work involves them participating in high-risk sexual activities for payment (anal intercourse) with multiple partners, regard themselves (thanks to the duality of their social position as described earlier) as paragons of masculinity, and thus of normality, when they are not engaged in the socially and culturally “questionable” activities that their profession entails. The combination of economic motivation and the insertive role that “bugarrones” take in paid sex means that their “real” and “normal” social identity and sexual orientation are not called into question.

De Moya and García (1998) explain that men who engage in paid insertive anal sex with men also take the insertive role in vaginal sex with women (whom they prefer), and thus consider themselves “normal”, definitely heterosexual, and quite different from the more “stigmatized” and “deviant” sex workers who play receptive roles in the Dominican Republic.

Many of the members of the security forces are young, spend much of their time on the streets, belong to impoverished socio-economic classes and earn barely the minimum wage. Although this does not necessarily mean that they have to engage in occasional sex work,

there is the possibility that a number of them might participate in the street sex industry (sometimes as sex workers and sometimes as controllers of female sex workers), while at the same time maintaining a “normal” identity in their personal lives. Some security force agents may participate in the sexual/informal economy of the street to supplement the low wages they receive in their formal occupation, thus occupying a frontier position between the two worlds as they maintain families, children, and wives and/or girlfriends who are unaware of their “other” occupation. In other words, many of these security force agents may regard sex work as a casual occupation that supplements their “normal” profession.

By spending so much time on the street, and in many cases participating (albeit casually) in the sex work industry, security force agents enter into close contact with high-risk groups. Those security force agents that participate in one way or another in sex work take the insertive role in anal intercourse. Both “bugarrones” and security force agents, then, merit particular attention as possible agents of infection in high-risk communities, owing to their ability to participate in the sex work industry and at the same time to regard their normal lives as being outside the sphere of their high-risk practices. One consequence of this is the attitude of unconcern about infecting partners that was displayed by all the security force agents interviewed, who were unwilling to use condoms with their steady partners “unless something is suspected”, and the attitude of the “bugarrones”, who would not use condoms with a woman who was “known” or “one of us”. This must be a cause for concern, and indicates a need for awareness-raising measures.

The fact is that while these attitudes about condom use with “steady partners” and “known” people are characteristic of Dominican men in general, they are particularly dangerous in a demographic group that is constantly crossing the narrow line between the social environment of the streets, with its practices, standards and risks, and that of the home, where they can shed their transgressive lifestyles and adopt an identity that fits in with generally accepted social rules.

Given these considerations, it is vitally important to understand how the attitudes of respondents in respect of the risk of AIDS infection differ depending on the way they “see themselves”, i.e. on the social environment in which they situate their public identity (even if this contrasts with other social circles in which they move). It is not hard to understand why transvestites, who cannot adopt “normal” social roles outside of their working environment owing to the sociocultural stigma that applies to conjugal/established relationships between people of the same sex (although they do not regard themselves as having the same gender), and who therefore occupy a personal situation that is similar to their working one, tend to take a more informed approach to the risk of infection to which they are exposed. As it is more difficult for transvestites to shed their “street clothes”, they understand that they are running a high risk of infection both in their sexual relations with customers and in their sexual relations with their steady partners or lovers.⁴

It is these frontier groups such as security force agents and “bugarrones”, then, that merit more thorough study because of the way they participate in social environments that can entail a risk of infection to themselves, to people with whom they have sexual relations

⁴ This new attitude among the transvestites, their willingness to take preventive measures in both their personal and working lives because they understand that they are in a position where they risk infection, is illustrated by remarks like: “Much as I love him and adore him, I don’t think anyone’s faithful in this world” and “[the situation is] difficult, because some of us and some of our customers are positive, but they don’t let on ... although we protect ourselves with condoms”. “It’s different now, we transvestites all use condoms.”

on the street, and to their partners in private and “normal” social environments. These groups that inhabit “the frontier” between the “street” and the “home” can play a key role in programmes to prevent infection and assist people at risk, specifically because of the way they move in the street and home environments simultaneously. In addition, they tend to have greater negotiating power in paid sex, owing to their mainly insertive role (and their heterosexual orientation) and to their understanding of the “rules” and “accepted standards of behaviour” of the streets.

Occupational discrimination and legal protection

As is pointed out in the situation and response analysis that accompanies this document (section 5.4.5), Law 55-93 on AIDS, which was passed and enacted in 1993, seeks to promote and protect the civil rights of people who are HIV-positive and suffer from AIDS. Although this law is well-intentioned, its scope needs to be adjusted in many ways if it is to provide a legal means of redress for the majority of people affected by HIV/AIDS.

According to the accounts of the respondents, among the families and individuals affected by HIV/AIDS many had been dismissed from their jobs when they were discovered to be HIV-positive, and in some cases the employers themselves (although no specific names were mentioned) carried out HIV testing on their employees and dismissed those who proved to be HIV-positive. None of the families affected, or the respondents themselves, gave any indication of knowing about law 55-93. Although this law has been in force since 1993, it has never been used as a legal means of redress by people with HIV/AIDS.

There are a number of reasons why law 55-93 has so far been little more than a dead letter. The main ones include ignorance of the law among many lawyers and judges right across the court system of the Dominican Republic, ignorance of the law among the general public already mentioned, and the fact that the majority of the people who could benefit most from this law, people with few resources and with no social or political voice, work within the informal economy, where legal regulation and court action are much more difficult. Perhaps the factor that plays the greatest role in making this law capable of responding to the legal needs of HIV-positive people who are discriminated against, and that makes it inaccessible to them, is the lack of anonymity in the legal processes that would be used to defend their rights under this law.

In the Dominican Republic, the socio-economic and cultural stigma against people who are HIV-positive is so great that the vast majority of them, particularly those who retain a “normal” identity and a healthy position in society (a home and the respect of their neighbours and, in the case of those who work in non-stigmatized jobs, their colleagues), would prefer to suffer in silence and/or accept the stigma and the feelings of guilt and shame that society assigns to them, rather than initiating controversial public legal proceedings against what are usually powerful companies or institutions that practise discrimination.

For law 55-93 to provide a real legal means of redress for HIV-positive individuals suffering discrimination, it is absolutely essential that it be amended to allow for proceedings in camera that protect the identity of the person seeking protection under it, and that the legal and judicial community, communities at risk and civil society as a whole be educated about the existence of this law as an important legal safeguard. All of a piece with the need to spread information about law 55-93 among all socio-economic strata is the need to set up non-profit-making legal advice and assistance centres in areas where they are accessible to

people with few resources, and to ensure that these are staffed by lawyers who can help them to initiate proceedings against institutions that violate their rights.

The cultural challenge of accommodating the HIV crisis in Dominican society

The HIV/AIDS crisis has shed light on the complex sociocultural structures of the Dominican Republic. These shifting, fluid structures interact dynamically with political, linguistic, economic and religious conditions and institutions to negotiate, and in part to govern, the interactions between Dominicans and the different milieux in which they lead their lives.

We shall therefore conclude this analysis of the cultural factors that influence the situations of people affected by HIV/AIDS by discussing the differential treatment that established institutions (both formal and informal), and particularly support institutions, give to people at the asymptomatic and symptomatic stages of the illness.

Among the subjects that were continually brought up and emphasized in the accounts given by the respondents, the following are particularly important as, taken all together, they demonstrate the challenge posed by the HIV/AIDS crisis to the established social structures of Dominican culture:

- The tendency for the people interviewed to establish a physical and emotional distance between themselves and asymptomatic HIV-positive people. This tendency, which was expressed in what those interviewed said about people close to them with HIV, illustrates the sense of mistrust and threat that many of them felt in relation to asymptomatic HIV-positive people.
- The tendency of HIV-positive people to conceal their state from most of their community, “warning” only those closest to them about their situation, and the disapproval of this practice among friends and people in the community.
- The common practice (which has been illegal since law 55-93 was passed in 1993) of dismissing asymptomatic HIV-positive people from their jobs. In some cases, the practice of testing employees to evaluate promotion prospects.
- The restoration of solidarity and care structures to draw symptomatic AIDS sufferers back into circles of support. The gender-based division of labour in caring for HIV-positive individuals suffering from opportunist illnesses.
- The special care taken by layers-out and burial workers with people who have died of AIDS.
- Attendance by large numbers of friends and neighbours at the funerals of people who have died of AIDS.

Taken all together, these recurrent features of the accounts given of the experiences of HIV-positive people begin to clarify the ways in which dominant structures of social and cultural behaviour are affected by the reality of AIDS. The imminent reality of HIV/AIDS, an incurable disease transmitted mainly by sexual contact, is necessarily undermining the institutional framework of social structures (probably ancient ones) that were previously perpetuated by means of an unavowed system, as part of the collective subconscious. In general, the HIV/AIDS crisis being experienced by Dominican communities makes it

imperative for established activities and viewpoints to be re-evaluated and redefined to accommodate, understand, describe and put into perspective the new reality of the epidemic.

As has already been discussed, asymptomatic HIV-positive people are generally abandoned by many of the people with whom they used to interact constantly before their positive status was known. In a considerable number of cases, neighbours stop visiting their homes and “instruct” their children not to interact with the HIV-positive person or their family. People in general feel mistrust and in many cases fear of becoming involved in the personal life of a HIV-positive person and being infected in the process. Consequently, we hear respondents saying:

“My family told me to keep myself to myself.”

“They told me to steer clear of her. I treated her virtually the same as always, although I was afraid.”

“The people she worked with left her alone. They deserted her.”

“My family told me not to visit that house for the time being ... but I went there more often to find out about the disease.”

“Her family said she had leukaemia, they didn’t want to tell the truth. I spoke to some other shoe-shiners. They told me to be very careful if she fell in love with me.”

Largely owing to a lack of education among the general public about HIV and the ways it is transmitted, many people feel threatened and endangered by the presence of an HIV-positive person in their lives. Someone who is apparently healthy, independent and in control, but is carrying HIV, a powerful symbol of death and one which among many people evokes images of perversion, sex, promiscuity, homosexuality and infidelity, is in many cases perceived as a threat not just to physical health but also to the social health of a community.

In many communities, affective, occupational, community and even religious structures break down and become unbalanced because their active components, people who move in these circles, feel threatened by a “disembodied” evil that is not visibly malignant (and that is a little magical), represented by the asymptomatic person. It is not surprising, then, that most HIV-positive people and their families try to conceal their state both when they are asymptomatic and when they are suffering from AIDS, opting at this latter stage to suspend the official title of the disease they are suffering from and give it another one that is somewhat less stigmatizing and awkward, and is better known and understood by society (such as a tumour, cancer or anaemia, among others).

One of the observations that we have been able to arrive at through the accounts of the respondents is that the imbalance and diminution or suspension of the social structures and interactions available to an asymptomatic HIV-positive person are partially corrected during the symptomatic stage of the infection. They reported that while many people abandoned HIV-positive friends and family members while they were asymptomatic, or when they showed only slight symptoms of infection, they re-established a care and counselling network when these people “fell” ill with AIDS, i.e. when they developed opportunist illnesses.

The descriptions given by the respondents explain that during the AIDS stage:

“His mother and a sister looked after him, his mother bathed him and gave him the medicine ... His neighbours and friends behaved well, but some of them didn't want to go near him. They were disgusted by him. Some of them went to see him in hospital, but others didn't, because they were frightened of catching it.”

“His mother, grandmother and neighbours washed him, others helped to do the housework. The neighbours helped look after him. There was no particular group that helped him, but a lot of neighbours did.”

“Her mother looked after her. One sister helped her, but she concentrated more on the housework. One boy did the errands. I spoke to her mother, but the people who helped her most were the ones from the church. The neighbours grumbled, but they always visited her, especially the Evangelicals.”

“Her brothers helped with money. The neighbourhood committee helped with a collection. She was admitted twice to the Padre Billini hospital. The neighbours visited her and took her fruit juice.”

During the AIDS stage, the main support structures such as the family, neighbours and the church, although they still maintain a degree of distance and take special measures for their own safety, resume their caring roles and their “control of the hazard” that the HIV-positive person has hitherto represented but no longer does, as he or she is living in a state of suffering and is partially or totally dependent on these structures for survival. This is illustrated by the way care of a person with AIDS is divided in accordance with the gender of the carers. For example, women tend to take care of the sufferer's hygiene and cleanliness, while men tend to contribute money for his or her maintenance.

It is at the stage where sufferers lose their independence and resign themselves to the care and power of others that caring structures, divisions of labour, support systems and systems to eradicate the malignant entity come back into operation, albeit somewhat cautiously.

It is very important to note that, after the death of an AIDS sufferer, many of the social support structures are reassembled, but special measures are taken to prevent and neutralize the “evil” represented by HIV. Prominent among these measures are the burning of the clothes of people who have died of AIDS⁵, the special precautions and taboos observed by many burial workers when burying people who have died of AIDS, and the participation of the bulk of the community in wakes and burials, as if they wished to reassure themselves that AIDS had disappeared from their lives through this process of social exorcism.

The wholesale participation and “solidarity” of the community after a death is illustrated by the following extracts from the accounts of respondents:

“I never spurned him, I was always there for him. My family arranged the funeral. After he died, people changed. They wanted to make amends, but he had gone by that time.”

⁵ It is possible that the burning and/or burying of the clothes of people who have died of AIDS owe their origin to practices associated with the control of other infectious diseases, such as tuberculosis and syphilis.

“She wasn’t bedridden for long; when she fell ill she died. The neighbourhood council and those of us who lived in the area raised money for the funeral. The whole neighbourhood contributed.”

The differences in the way symptomatic and asymptomatic people are treated by the communities and institutions to which they belong are due in part to a lack of reliable knowledge about AIDS infection and prevention, and in part to the variety of different viewpoints that shape the perceptions and representations surrounding the understanding of AIDS as a social symbol among Dominicans. It is particularly important to recognize the magical attributes that are ascribed to HIV/AIDS (as an incurable, disembodied spectre that enters the body through (highly taboo) sexual relations, especially those that are tainted as illicit) and that influence popular reactions to the human reality of the disease.

It is imperative for AIDS prevention programmes to take account of the many cultural factors that influence the attitudes of large sections of society towards people who are infected or have AIDS, and for these cultural factors to be incorporated into the approaches and strategies of these programmes. Only when the reality of the AIDS crisis is understood in context can a start be made on implementing sensitive, respectful and sustainable prevention and assistance programmes.

Objective 4. The needs of deprived groups and methods of dealing culturally with those needs

Almost without exception, the people interviewed in the course of the fieldwork done for this cultural approach asked for education campaigns dealing with HIV/AIDS infection and methods of prevention, and particularly condom distribution programmes, to be increased, expanded and carried to all risk groups. Similarly, many of the respondents asked for more substantial and accessible medical assistance for people infected by HIV/AIDS.

The main emphasis of the recommendations put forward by the young people interviewed was on the pressing need for condom distribution campaigns, aimed specifically at sex workers and, among these, at those working on the streets in urban centres and deprived areas. This was the message of a “bardaje”/transvestite who explained that condoms “don’t arrive ... sometimes the women (female sex workers operating alongside them) don’t have them.” The same respondent suggested that the Public Health authorities “should go out into the streets and give house-to-house advice, in La Feria.” A number of other interviewees identified a lack of institutional support for those infected with HIV, and emphasized the crucial need for patients with AIDS to receive primary and secondary health care.

In the Dominican Republic, cultural taboos and hegemonic social rules contribute to the socio-economic and cultural exclusion of people infected by HIV, mainly during the asymptomatic stage, until the stage of the illness at which they are “deserving of comfort”, “vulnerable”, “not self-sufficient” and under the control of those same hegemonic factors and taboos that govern society. One result of the social exclusion of people infected by HIV is the lack of financial support from the Government and other sources of support for an institutional network of care for these people. Organizations that work to improve the quality of life of people living with AIDS, for example through counselling and legal representation, help with jobseeking, nutrition and other important programmes, are thin on the ground or non-existent, particularly in disadvantaged areas. Consequently, it is not difficult to understand the conception that most Dominicans have of an HIV-positive state as signifying imminent death.

While most respondents had a rudimentary knowledge of how HIV was transmitted, and all of them had experienced at least one case of a person close to them being infected by the virus, many of them were quite ill-informed about HIV transmission and prevention methods, and engaged in a variety of activities that put them at risk. This situation is illustrated, for example, by the popular belief among groups of young sex workers that the penis “sucks in” HIV through a “gap” created at the moment of ejaculation (De Moya and García, 1998). This “understanding” of how infection takes place sustains the idea that taking the insertive (active) role during anal intercourse is riskier than taking the receptive (passive) role.

Ignorance of the role played by preseminal fluid in the transmission of HIV was displayed by one of those interviewed, who explained that, to protect himself against HIV infection when he took the receptive role in anal sex, he did not allow the man taking the insertive role to ejaculate inside his rectum. Other respondents declared that although they understood the importance of using condoms both with customers (in the case of sex workers) and with partners “for pleasure”, there were conditions under which they would not regard condom use as necessary (or appropriate). Under these conditions, unprotected sex with “known” people or people who were “one of us” was regarded as risk-free.

Perhaps the point that was emphasized most strongly in the statements made by the respondents, and to which we referred at the beginning of this section, was the isolation of people living with AIDS from the solidarity networks and social and caring structures of disadvantaged communities, and from social support groups (such as churches, neighbourhood committees and other informal support agencies) in their communities. In the accounts that the people interviewed gave of the experiences of friends and acquaintances with AIDS, the almost universal assertion was that “no particular group helped them” (i.e. people living with AIDS). There are groups that, exceptionally, were identified by those interviewed as having given help to HIV-positive people in deprived areas. Among these, the group “Propuesta de Apoyo a la Vida”, the self-help group of Santísima Trinidad parish and other religious groups received frequent mention. No reference was made by the respondents, however, to groups providing education on HIV prevention in disadvantaged areas, a fact that brings home the need for education campaigns of this kind to be carried out as a component of sustainable development programmes in this area.

Most of the respondents knew about the existence of the AIDS test, and a number of them said that having the test done was a prerequisite for unprotected sex with a partner. It is crucial to note, however, that the HIV test *is not free* anywhere in the Dominican Republic, and that this represents a great obstacle to having the test done for most of the people who may be at risk, especially those who are badly off financially. As a central component of prevention programmes, the HIV test is especially important in the Dominican Republic, a country where most people equate a positive result with imminent death, where there is a high level of economic inequality between the groups most affected by the HIV crisis and the rest of the population, and where many people impose a linguistic hiatus on references to HIV/AIDS as a way of neutralizing and denying the reality (or possibility) of this in their own lives. Many respondents who claimed to confine themselves in their choice of steady partners to women who were both “known” and tested (and HIV-negative) let it be implicitly understood that knowing the partner was, in most cases, a sufficient condition for having unprotected sexual relations.

Providing access to free testing centres would unquestionably help to overcome the obstacles that stand between the possibility (to which many respondents refer) and the reality

(for them) of taking the HIV test. The establishment of anonymous testing centres, together with wide and sustained condom distribution in deprived areas, the development of a rudimentary institutional support network for HIV-positive people in disadvantaged areas both in urban and periurban districts and in the countryside, and the institution of education campaigns designed to counteract the social stigmatization of HIV-positive people, should be the main components of a sustainable, sensitive and respectful programme of action.

Objective 5. Identification of priority issues for future research and strategy

On the basis of the interviews with the respondents and analysis of these, we have identified the following issues as priorities for future research and action in the HIV/AIDS crisis among young people involved in sex work and street culture:

Condom distribution programmes, free HIV testing units with counselling, and education programmes tailored to the needs of communities at risk.

- Testing units offering free and anonymous HIV tests to people who show that they have engaged in high-risk behaviour should be set up with cooperation and training from staff working in community organizations that operate in the health-care sector; these stations should combine condom distribution with education and counselling sessions, introducing people who prove to be positive to self-support groups and health services available close to their homes or workplaces, to alternative forms of employment or income-generating activities, and to legal support and counselling resources in the case of people who have been discriminated against;
- A start should be made, with the participation and support of the relevant grass-roots community organizations, on recruiting, training and organizing young leaders from deprived groups and street culture who can take on responsibility for distributing condoms, producing their own educational material, carrying out preventive education and counselling other young people in their communities;
- Numerous condom retail points should be set up in accessible positions so that condoms can be obtained at all times of day, and at subsidized prices, by all types of sex workers and their customers;
- Potential condom distributors should include natural leaders in communities of sex workers whose behaviour is acceptable within their own groups, particularly in newly-formed groups of minors carrying out sex work, and established street sellers (i.e. “paleteros”, fruit or flower sellers), tyre repair centres (open 24 hours a day), beauty salons and barbers, among others; this initiative should meet the requirements of anonymity and confidentiality for each distributor;
- An educational component should be designed on a participatory basis, focusing specifically on “frontier groups”, i.e. on those who frequently cross the dividing line between “the streets” and “the home” and are thus at a higher risk of infection than they realize or acknowledge;
- Training programmes that respect traditional beliefs should be initiated for people, such as folk healers and psychics, who could play an important role

among deprived communities by giving counselling and emotional support to people living with HIV/AIDS and their families.

Campaigns in a variety of media tailored to the needs of the general public, focusing on the following:

- The role of blood, preseminal and seminal fluid and the HIV immunological window period, and the use of condoms for physical prevention of HIV infection;
- The inclusion of education about other sexually transmitted diseases and prevention of these, their potential to remain asymptomatic in women, and explanation of the increased risk of HIV transmission associated with ulcerative STDs;
- Arguing for the deferment of sexual initiation and for sexual abstinence as a right to which all people are entitled and which offers sure protection against STDs and HIV/AIDS;
- The campaign should include the use of personalities who have acquired the status of cultural icons, particularly those whose popularity extends over a number of social strata; we suggest, for example, a campaign using the baseball player Sammy Sosa, with the indirect condom promotion message (taken from the interviews) "I'm not going in bare-handed" (without his glove). Similarly, campaigns using famous *merengue* singers such as Millie Quezada can focus on other, more traditional, aspects such as abstinence and monogamy.
- Starting to get away from notions such as "fidelity", to take away the stigma of suspicion from the idea of condom use, and delivering a message that questions and breaks with the "street/home" and "acquaintance/stranger" dichotomies; this could be achieved, for example, using the message (taken from the interviews) "Anyone who doesn't want to use a condom may be sick", in opposition to the current implication that the decision not to use a condom denotes fidelity to one's own partner.

Suggestions for further research

- The difficulties involved in organizing and training leaders in communities of sex workers, who value their anonymity; there is a need to draw on the experience with community involvement of NGOs working with these people (Rosario *et al.*, 1994, 1996).
- The dynamic of sexual interaction in networks of sex workers, customers and steady partners, and the way frontiers between the street and home cultures are crossed.
- Appropriate strategies for involving strong community organizations in the work of research-action, sustainable development, preventive education, counselling and emotional and tangible support for people living with HIV/AIDS.

Conclusions

This study has organized its ethnographic and textual data into the following five related objectives: (1) the HIV/AIDS crisis, sex work and the informal economy; (2) and (3) cultural resources and factors: their relationship with the HIV/AIDS crisis and their role in ensuring that action is relevant and efficient; (4) the needs of deprived groups and methods of dealing culturally with those needs; (5) identification of priority issues for future research and strategies. Our findings can be summed up as follows:

(1) The HIV/AIDS crisis, sex work and the informal economy

There is an economic crisis in the Dominican Republic which is making it difficult for many individuals and families to generate enough income to meet their basic needs.

- As a result of this crisis, there is an active informal economy in which goods and services are traded without official monitoring or approval, and from which many members of deprived communities derive modest incomes.
- In a highly stigmatized form, sex work plays a significant role in the informal economy and provides many women with employment. Most of their customers are Dominican and foreign men, while a smaller number are foreign women. As a result of changes in sexual habits since the 1970s, the number of adult and adolescent males deriving income from sex work has increased. Most of the people who become involved in sex work do so only when they have nowhere else to turn.
- By its nature, sex work is an activity that carries a high risk of infection by STDs, including HIV/AIDS. Among communities of sex workers in Santo Domingo, sex work can be classified by the gender of the person performing it, the insertive or receptive role played, the type of vaginal, anal or oral practice (or a combination of these), and the personal or private sexual conduct of the sex worker.

(2 and 3) Cultural resources and factors: their relationship with the HIV/AIDS crisis and their role in ensuring that action is relevant and efficient

Generally speaking, condoms are used “negatively” rather than “positively” in Dominican culture, and are associated with ideas of fidelity and of a rigid and unreal divide between “the home” and “the streets”.

- People are reluctant to articulate the words “HIV” and “AIDS”. This reluctance is symptomatic of the efforts of many communities in poorer areas to deny the reality of the HIV/AIDS crisis and make it disappear from the personal areas of their lives. This avoidance of the words “HIV” and “AIDS” was exhibited by people recounting the experiences of those close to them who had been affected by the virus, and thus illustrates how this reality has entered into many people’s lives.
- For a range of cultural reasons, including the role they play in paid sex work and the nature of their personal/private sexual activity, and the non-sexual nature of their “primary” economic activity, “bugarrones”, security force agents, “palomos”, “sanky-pankies” and “pimps” tend to regard themselves as “normal”

and do not project the stigma associated with sex work on to their cultural identities. For the same reason, however, many of them do not follow safe sex practices in their personal/private sexual activity as other groups do, for example the highly stigmatized “bardajes”/transvestites. These “frontier” groups represent a particular risk factor for STD transmission.

- Just as there is a “linguistic hiatus” represented by the substitution of the word “it” for “HIV/AIDS”, there is a tendency for families and individuals affected by the disease to conceal its identity and “redesignate it” as a disease that is better known and less stigmatized by society (such as cancer or anaemia). This concealment is highly criticized by communities, which feel that they are being threatened and endangered by some people who do not reveal their positive state. This concealment of HIV infection is both symptomatic and productive of the social stigma that surrounds HIV/AIDS.
- Social structures (occupational and support networks, among others) that were previously fluid and “understood” by society have had to be re-evaluated, especially as regards attitudes towards social assistance in the face of the reality of the HIV/AIDS crisis. Ignorance about infection methods means that many support and interaction structures break down during the asymptomatic stage of the infection because many people feel threatened and endangered by a “disembodied” and poorly understood entity represented by the HIV-positive person. HIV-positive people who look healthy and who can interact “normally” with society are seen as an enigma and a threat because of their power to infect.
- Many of the structures that are suspended during the asymptomatic stage are restored, in a special and cautious way, during the AIDS stage, and after the death of an AIDS sufferer. It is possible that the reason for their being restored is that people in these structures (neighbours, friends, family members) regain control over the AIDS sufferer.

(4) The needs of deprived groups and methods of dealing culturally with these needs

A number of priorities for HIV/AIDS prevention in communities at risk can be identified from the accounts (and striking omissions) of the respondents:

- Education campaigns dealing with the transmission and prevention of HIV and other STDs need to be implemented both in communities at risk and among the population at large. They need to place emphasis on removing the stigma surrounding people who live with HIV or AIDS.
- Programmes to distribute condoms at low cost (so that the distribution programme can be sustained) should also be established to provide a reliable and accessible source for poor communities at risk.
- More substantial, financially accessible sexual health programmes need to be developed to treat people with sexually transmitted diseases (STDs), including HIV.
- Institutional support networks need to be created, including in particular legal, medical and employment counselling services.

- Programmes and institutions offering free HIV testing should be developed. Testing should be accessible and anonymous for everyone, with special emphasis put on communities at risk.

There is also a need for sustainable mechanisms through which the priority measures set out above can be implemented and continued over the long term. These mechanisms for implementing prevention and assistance programmes need to take account of the economic reality that has made the large Dominican sex industry possible, and need to provide economic solutions to the problems from which it suffers, as well as cultural and social ones. In particular, there is a need to provide employment opportunities that are realistic (given the academic level of the people concerned, and the incomes and options provided by commercial sex and other trades within the informal economy) and relatively safe for female sex workers.

It is therefore very important to concentrate on the following:

- developing short-term specialist training programmes that provide an opportunity to get out of the sex work industry for those who wish to leave it and take jobs in the formal economy;
- at the same time, developing cooperatives and coalitions of sex workers that can offer services (drawing on the skills learnt on the specialist courses) to their community and occupational group, thereby enabling incomes to be maintained within that community;
- using people who belong to communities at risk as educators, condom distributors and peer counsellors, among other assistance roles.

(5) Priority issues for future research and strategy

This section explores a number of issues and concludes that the following are needed:

- the establishment of condom distribution programmes and clinics to provide medical counselling, carry out HIV testing and treat STDs, free of charge;
- the establishment of direct education programmes aimed at high-risk groups, that take account of the cultural and socio-economic factors predominating in those groups;
- education and prevention campaigns disseminated through the public media which use ordinary language and popular icons to get their messages across.

This section ends by identifying important issues for future research.

The research process and social analysis that this cultural approach entails have led us to conclude that the HIV/AIDS crisis in the Dominican Republic is characterized by the clash between prevailing sexual ideas and practices, many of them related to the economic survival of deprived groups, and the fact that these practices provide the main avenue for infection. It is imperative to recognize that popular education to teach people how to avoid HIV infection must be a crucial component of a sustainable, sensitive development plan that respects the needs of deprived groups, particularly young people involved in the informal economy and in street culture.

The social and economic conditions that characterize this street culture are among the factors that cause the young people who are subjected to them to be stigmatized, excluded and silenced by dominant social groups and values. As we conclude the process of analysing those cultural factors that are relevant to the HIV/AIDS epidemic and the role in it of disadvantaged groups, we would emphasize that any plan to prevent HIV/AIDS, if it is to achieve sustainability and a long-term impact, needs to involve vulnerable groups as active participants in its planning, implementation and evaluation. For these groups to be included as active participants in the development of HIV/AIDS prevention programmes, the action strategies that are established will need to take account of the structural and social conditions that put them at risk of infection.

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APPENDIX

Summary of Interviews

Adolescents and young people in deprived population groups

“Bardajes” or transvestites

Three young male sex workers, regarded as “bardajes”⁶, were interviewed in sex work areas of Santo Domingo (Avenida Duarte, Centro de los Héroes). Their ages were between 19 and 20, as it was not possible to meet any minors among them. Their sexual initiation had taken place between the ages of 12 and 16. All three had obtained their baccalaureate, they had no children, and their financial situation was precarious. Two of them each lived with a male partner.

In relation to the HIV/AIDS situation, they said that they knew between two and eight HIV-positive people, some dead and others still living. They described the situation as “difficult, because some of our people and some customers are positive, but don’t let on ... although we protect ourselves by using condoms”. “It’s different now,” said another, “we transvestites all use condoms.”

As regards educating their children, should they have any, about AIDS, one of them said that (s)he would tell a male child to “use a condom with any girl, because you can catch gonorrhoea, just like that” while another’s advice would be that he should “know who he was doing it with”. One of them would tell a daughter to remain a virgin until she got married.

Sex work was seen as a job by the group. The family of one of them did not know that (s)he “goes looking for it in La Feria” and thought (s)he went off to work in a different business. Another said (s)he did it for pleasure, “because I want to see my friends and customers”. The third said that “in other countries prostitution is a job. Here it’s not appreciated, it’s something marginal. That’s how I cover my needs, pay for my house”, although “my work is not well paid”.

They regarded female sex work as something that women did out of economic necessity, “because her husband’s left her, she has children to bring up and she hasn’t got a job ... but please, she should protect herself”. They tended to be disapproving of women who paid men money for sex, because they believed that “there should be love there ... but I don’t judge anybody”. They thought it was justifiable for one man to give money to another for sex, “if they are lovers”, but if not “the one to blame is the one who is using him”, while the other is “a *bugarrón*”.

Important changes in sexual conduct were reported: “I’ve noticed that men are staying at home more. They prefer to be with their steady partner because they’re frightened of AIDS.” Another added: “Everyone uses condoms. Customers demand it to avoid getting infected. A lot of them give us advice. You have to put a condom on them to suck them off and have sex. I start with oral sex. I know what I’m doing. I don’t take any notice of what they want. Others don’t want to use one, but they could be sick.”

⁶ A “bardaje” is a man brought up as a woman, who wears women’s clothing and adopts feminine gestures and forms of speech. In urban areas, most of these people carry out sex work, and they are known as “travestis” or transvestites. In the capital, they have the highest rates of HIV infection (34%), resulting from unprotected receptive anal sex with multiple partners (Tabet, De Moya *et al.*, 1995).

As a precondition for having sexual relations without using a condom, they said that it must be with someone they knew who had had themselves tested for HIV. "If we're going to get together as a couple, we both go and have the test. If it's for one night, then it's protection and no oral sex."

There was a clear awareness of the pitfalls of fidelity: "Much as I love him and adore him, I don't think anyone's faithful in this world." "You don't know what he's up to out there in the streets." "I always use them, because just as I do it with my boyfriend, I'll do it with someone else."

All were agreed that if their partners proved to be HIV-positive, they would continue the relationship, keep them company and support them: "I would support him and I would never leave him, but there are so many things I would cry about. I would look after him, protect him and make him understand that I'm there for him."

As regards preventing infection, they wanted the Public Health authorities to disseminate information about AIDS, and they thought there should be better education, covering the whole country. "They should go out into the streets and give house-to-house advice in La Feria ..." They also said that condoms "don't arrive ... sometimes the women (female sex workers) don't have them". One of them ended the interview with an exhortation: "Transvestites! I know street life is hard, but take care of yourselves!"

They were asked to talk about the AIDS case to which they had felt the closest emotionally. The first case was that of a female professional friend, aged 40, divorced, with two children, and now deceased.

She was always nervous. While she kept it quiet, knowing she was pregnant, the virus was killing her... Her children tested negative. After she fell ill everyone realized. Her relatives took her in and supported her, but they felt ashamed. They said she had a brain tumour. I was distressed when I learnt she was ill. As soon as you know that someone is down with AIDS, you know they're going to die. My mother and I told her to turn to the Lord. My mother told me we should treat her lovingly, particularly those of us who are on the streets, because we could get the virus. The people she worked with bought things for her and visited her. They supported her. She belonged to a group at the National Laboratory, she went to the talks when she could. The doctor from there visited her and took her medicine.

The second case was that of a gay friend, aged 22, now deceased, who could not accept the fact that he was HIV-positive.

He lived with his lover, who was HIV-positive as well. They felt bad because the neighbours kept saying things to them and didn't want to go near them, because they were afraid ... They thought the walls were infected. I spoke to my family and told them I felt sorry for my friend. They never told me not to care. On the contrary, they said I should support him. I gave him advice. He spent a lot of money coping with the illness. His lover's family gave him a bit of financial help. His parents' closest relatives helped out, both men and women.

The third case was that of a close friend, aged 17, who had worked as a transvestite dancer in a gay club, and who had died. He had got his baccalaureate and had taken courses in computing and English. His financial situation was precarious.

When they realized he was HIV-positive they threw him out of his house ... As far as they're concerned it's ... an aberration for a man to sleep with another man. They isolated him and got him out of their lives. His family regarded him as a contemptible creature in society ... We called his father, but ... they didn't help him. On the contrary, they put the blame on us ... for his being a homosexual and getting ill. The neighbours found out straight away, because he was getting worse and people aren't stupid ... They didn't give him any support. His real friends supported him, but those who weren't his friends were pleased,

because in the world we live in there's a lot of gloating when we see other people going under. The only people who helped him were us, his friends, and the boys from ASA.

“Gays” or homosexuals by choice

Interviews were carried out with five males who described themselves as “gays”⁷ or homosexuals by choice. Three of them were aged between 15 and 17. They had had their sexual initiation at the ages of 5, 8 and 15. All three were single and none of them had had any children. They were secondary school students and had no job. Their financial situation was poor, precarious for one, and acceptable for the other two. They lived in poor, deprived areas of Santo Domingo. Two carried out sex work (“they go looking for it on the streets”).

The other two were both aged 23, and their sexual initiation had taken place at the ages of 13 and 16. They were single and had no children. They were in secondary and university education and working in carpentry and upholstery workshops. They lived in poor areas and their financial situation was unstable.

The younger people said that they had known between six and 20 HIV-positive people or AIDS sufferers. In their opinion, the situation with the disease was getting worse and worse – it was “slightly concealed, but it’s everywhere” – and it was very widespread among young people. One of them said, “you have to be very careful with the ‘chamaquitas’, those are the women that ‘cut’ (infect) you”, suggesting the possibly bisexual nature of sexual relations at these ages. The older ones had known two or three people who were HIV-positive or had AIDS. They regarded the situation with the epidemic as “quite alarming” and having “gone too far”.

If they had a male child, the younger gays would give him advice about “what AIDS and some venereal diseases are like and tell him to protect himself, to stay with one person, not to go around sleeping with everybody”. They would tell a daughter the same, they would “educate her”. The older men would tell their children, whether male or female, that AIDS was an incurable disease, while they would advise their male children to use condoms and their female ones to demand that their partners did so, and tell them not to share sharp objects.

The younger men had been told by people that “they should change their lives”, a reference to their homosexual practices. Despite their youth, however, they said that they believed they were doing the right thing: “I’m a homosexual and I like being one ... I always will be, and I’m not going to change ... they criticize me, but I don’t think it’s a crime ... I live an acceptable life.” The older ones said that they had earned respect and that they lived normal, calm lives with which they were very happy.

The two youths who were sex workers tended to justify female sex work by saying that women “aren’t going to do the work for free” and that it was “a way of earning a living”, although “not a decent one”. The other one, however, regarded it as “very vulgar, very common ... it’s something you would expect of a very mediocre person ... it looks very bad”. The older men, who were not sex workers, said that it was “just too bad ... there are lots of jobs you can do ... but if that’s what they like, I respect their opinion”. It is interesting to note

⁷ In sexual relations, it is supposed that “gays” adopt the receptive or passive anal and/or oral role, but they may also adopt the insertive or active role, or neither of the two. Previous studies (Tabet, De Moya *et al.*, 1995) showed that this population group had a 12% HIV infection rate.

the differences in the motives ascribed to sex workers by those involved (necessity, work) and by observers (pleasure).

The same differences of attitude were seen in relation to the idea of a male receiving money for sex with a woman or another man. Some said "there are women who offer money, and we're not 'kids', so to get satisfaction you do it" and "if the boy needs money and a man turns up who offers it ...". Others, though, repeated that "that's just too bad as well ... the difference is the sex ... a man who does it doesn't have any self-respect". Regarding men who charged other men for having sex, one of the older ones said: "those people aren't even worth mentioning".

The younger ones said that they "have adjusted ... changed a bit. I use a condom with friends I go out with ... People protect themselves more now, but I've seen a lot of promiscuous people The old ones (fathers) give you advice, they've stopped going after 'chamaquitas', which is what they like". The older ones said that condoms were used more often now, and that they themselves used them.

As regards the conditions under which they would have sexual relations without a condom, the responses of the younger men were varied. One said he wouldn't do it, that he would demand protection from his partner. The positions taken by the others, however, were worrying: "I ask them who they've had relations with before ... then I know what to do ... I would get him to take the test, and if that was all right I would do it without a condom," maintained one. The person would have to be "very strict, and it (the semen) mustn't go inside", said the other. The older men, for their part, said that one of the conditions for starting up with a new partner was that they both had the test done (something that would be difficult to do with each new partner), although they added, "particularly if I don't know him" (suggesting that if they did know him they would probably not use a condom).

All in all, these statements reveal a poor understanding of the fallibility of selection criteria, the role of preseminal fluid in intercourse, and the immunological window period in AIDS testing.

The younger ones believed it was "highly advisable" always to use a condom with their partners, and said that they used them, "because I don't know if he protects himself" (with other partners). Similarly, the older men said that "they have to be used always. I don't know if he's faithful to me. I always use them".

If a partner turned out to be HIV-positive, two of the younger men would not continue with him, although one of them would support him, and a third "would go looking for him to get my own back". The older men, however, seemed to be less rejecting: "I would treat him the same, and if I've got it, good luck to us both"; "I would put up with it and adapt to him".

As regards their advice to the Public Health authorities, the younger ones insisted that there should be better primary prevention: that people should be made more aware of the problem, that condoms should be handed out free of charge, and that there should be more publicity campaigns. The older ones emphasized secondary prevention: more hope for those infected, medicine or a cure, homes and hospitals for people with AIDS.

The 15-year-old told the story of a friend who was like a brother to him, who had died of AIDS. He was another youth of 16, who was in the second year of studies for the baccalaureate. He was married and had two children; in other words he was bisexual. He was

a stylist in a beauty salon and a sex worker. His financial situation "wasn't too terrible". The two had lived together in the same lodgings.

His family didn't help him out. They behaved very badly, very aggressively. They complained about him, said he might pass it on, they proclaimed it all around the neighbourhood. I talked to his family and told them that they shouldn't withdraw, they should help him out. Nobody in his family helped him. They gossiped about him and insulted him. In the salon where he worked, they got annoyed and wanted to sack him. Two of the people he worked with behaved reasonably well, they're the only ones there's anything to be said for. My family didn't object to my helping him, they supported me. I never spurned him, I was always there for him. My family arranged the funeral. After he died, people changed. They wanted to make amends, but he had gone by that time.

One of the two 17-year-olds referred to the case of a 24-year-old female neighbour who suffered from AIDS. She was in the first year of studies for the baccalaureate, was married, and had three children. She had worked in the sex industry before, but had stopped. She lived in a poor area.

The reaction of the family was harsh, they threw her out of the house. They didn't want to let on, they hid it for a time. That's very bad, because she carried on sleeping with a lot of people after knowing she had AIDS. I spoke to the neighbours. I stopped talking to her because of what she was doing. She had to move out of her house. Her children were very small, but I don't know if they were tested. Afterwards I treated her the same as anyone else, but I was a bit distant. I think people have been changing in the way they treat her, because they feel sorry for her. They treat her a bit worse because of what she was doing. The neighbours gave advice to the family. Her brothers helped her with money. She hasn't got any sisters.

The other youth, also 17, told the story of a distant friend, a sex worker who had AIDS. He was 24, studying at intermediate level, unmarried, without children. He did odd jobs in the neighbourhood and the financial situation of his family was good.

His family took it very badly, they were very upset. They've helped him out, but they should have spoken to him about it earlier. They didn't say anything at first, they didn't alert the neighbours. I didn't speak to him that much. My family told me to keep away. The people in the neighbourhood have helped. His father and brothers help him to cope with life. They've spent a lot of money on the disease. He's been in a very bad way.

One of the 23-year-olds referred to the case of a neighbour who had travelled abroad, and had now died of AIDS. She was aged 30-35, her level of education was unknown, she had three children, did not work, was "not too badly off" and lived in a poor neighbourhood.

She lived abroad before falling ill. When she was ill, her relatives treated her well. They didn't turn their backs on her. That's good. They didn't hide it, they were quite open. My family told me to treat her well. I carried on treating her the same. We comforted her. Her children had the test done and came out negative. Some neighbours who understood things treated her well, others with indifference. They came closer together. Since the family was well off, things didn't go too badly for them.

The other 23-year-old told the story of his best friend, who had died of AIDS. He was 18, homosexual and childless. He had his baccalaureate, did not work, had a stable financial situation and lived in a poor neighbourhood. His friend claimed that he had been infected by sharing needles, as he used intravenous drugs.

They reacted badly in his family, the wailing and lamentation started. They concealed it because they didn't feel that it should be common knowledge. That's a family problem. He told me about it in confidence. I talked to him about AIDS and how it's transmitted. My family told me to be careful of him. I carried on treating him the same as before, but more affectionately. His mother and a sister looked after him, his mother bathed him and gave him the medicine; the boys were only small. His neighbours and friends behaved well, but some of them didn't want to go near him. They were disgusted by him. Some of

them went to see him in hospital, but others didn't, because they were frightened of catching it. I didn't hear of any group helping him. The situation didn't change, as a lot of people didn't even go to the funeral.

Insertive homotropic sex workers ("bugarrones")

Interviews were held with three "bugarrones", sex workers who are supposedly insertive or active with men.⁸ The first of them, a "street boy" or "palomo" as they are somewhat dismissively called, was interviewed in a sex work area (Güibia beach). He lived on the streets. He was 16 years old and had had his sexual initiation at 11. He was in the sixth year of primary school, single and childless. He worked on a street food stall. He was badly off financially.

The other two were both 21, they had had their sexual initiation at the age of 13 or 14, one was studying for his baccalaureate and the other had completed it. They were both single and childless. One of them was a vehicle bodywork repairer and painter and the other was a member of the security forces. Their financial situation was stable. They lived in poor areas.

With regard to the AIDS situation, the first said that "AIDS is becoming a real nuisance, people are going down with AIDS all the time ... those 'cueritos' (under-age female sex workers) are all sick, you have to be careful". The others said that AIDS was "a tough one" and that the epidemic was at a "quite advanced" stage. The three of them knew two or three HIV-positive people or AIDS sufferers apiece.

All three were united in saying that if they had a son or daughter "I would give them advice ... and guidance ... just as long as they don't come down with something like AIDS ... I would teach them to make the wisest choice and always look after themselves ... I would tell them that on the streets you shouldn't trust anybody, and they should try to get to know the person first".

The youngest said that customers "take to me, they don't refuse me anything I ask. I think I'm doing all right as I am". The older ones said: "People always talk, but I take no notice. They don't say anything to me, they're afraid to ask me. I'm happy with it (my life). As long as I take care of myself, I'll be all right" and "I'm young and I'm happy with things. I like life and I don't like diseases, that's why I protect myself".

As regards female sex work, they dwelt on its pros and cons. Like the "gays", they tended to draw distinctions between the reasons for doing it, and included condom protection as a necessary condition: "On the one hand it's good, because they get money, but (on the other) it's bad, because when they fall ill the money's not enough for them to cure themselves." Another affirmed: "They need to look after themselves. A lot of them do it for money so that they can support themselves, because it's the easiest way." And the third added: "It all depends, because there are some who do it for pleasure, out of necessity, or because they are obliged to. I wouldn't advise anyone to sell their body."

On the subject of a man taking money from a woman for sex, the youngest said: "I wouldn't be comfortable with it." The other two said, without judging, that "they need to protect themselves as well, it's best", although "there are hardly any brothels where men

⁸ Generally speaking, these young men also have sexual relations for pleasure with women, and do not identify themselves as homosexuals. Their HIV infection rate was 8%-10% (Tabet, De Moya *et al.*, 1995).

work, unless they're gay brothels". Regarding homotropic sex work they said, somewhat defensively: "I wouldn't like to say ..." and "everyone's rights should be respected, but people need to take care of themselves too", although one argued that this practice was "pretty disreputable ... there are plenty of jobs that a man can do on the street".

There was not much agreement about changes that might have occurred in people's sexual habits. While one said "I don't think anything's changed, but in the places where I spend my time, I could hardly say", another said "a lot of them have changed. Everyone's got scared".

As regards their conditions for having sexual relations, whether with a woman or with a man, they said that "I would say no, if I didn't know her; if I knew her, I'd use protection ... I'm not going in bare-handed ... I don't like it very much, but you have to do it". Nor would they practise oral sex. If the woman were "one of their own people", however, they would not use a condom because presumably "she doesn't go out" with other men. "I would have to think about it a lot and know her well ... I wouldn't use a condom with her."

If a partner turned out to be infected with HIV, one said that "I would feel dubious, I would react badly", while the others said they would undergo analysis, go to a psychologist, buy medicine to keep going "until my time comes" and, "as for my partner, I can't take her life away from her".

In only one case was it suggested that the Public Health authorities take preventive measures: "They should try to make young people in the Dominican Republic more aware." The others suggested measures of a repressive type: "Pick up everyone with AIDS and put them in prison"; "they should start a home or somewhere where people who are infected can go to be treated, and they should keep them out of the way".

The youngest one recounted the case of a brother of his who had lived in New York, and died of AIDS. He was 27, had reached the first year of the baccalaureate, was married and had two children. The respondent did not know what kind of work he had done there; he was badly off financially, and he had gone home to his parents when he fell ill to die on a rural property in the south of the country.

Our relatives were terribly upset; we had lost one of the family. We had him deceived with lies; we told him it wasn't AIDS. That was a bad thing to do. I spoke to some friends of mine who were 15 and 16. They told me to treat him well, until his time came. I was sad; I treated him well. We were advised to treat him gently. His wife apparently was going to have the test. His children were grown up by that time. They seem to be all right. They're boys and in the end they all stick together. His family took care of him. It was hard, because he worked for them. The neighbours were very upset and sad, they were always going to visit him. A lot of people went to see him, but others didn't go near. I didn't hear of any group helping him.

The other sex worker recounted the story of a female friend of his, a sex worker who was HIV-positive and who was still alive. She was between the ages of 26 and 32, married with one daughter. She had got her baccalaureate, her financial position was precarious and she lived in a poor neighbourhood.

Her relatives were amazed, because they weren't expecting it. The family didn't hide it; they didn't turn their backs on her. I think that's the right way to react. She used to say, 'I've got AIDS'. A friend told me. My friends told me to keep away from her. We weren't very close and I distanced myself a bit more. At least her mother, uncles and brothers try to talk to her about it. Now I talk to her mother; I never leave her alone. The neighbours haven't cut her off: they treat her the same or perhaps better. She won

everybody's affection. Her daughter is negative and looks quite healthy. There are eight people in that household, and they work. This is the first time I've talked (about this) to anyone.

Male heterotropic sex workers ("Sanky-pankies" and "controllers" or "pimps")

Interviews were carried out with two young men who provided escort and sexual services to female (and frequently male) tourists on two of the country's beaches. They were aged 18 and 24, they had had their sexual initiation at the age of 13 or 14, and they were in the first years of the baccalaureate. Both were single and childless. One "sometimes" worked in a restaurant, while the other was unemployed. Both said that their financial situation was "middling". They lived in rural areas near the beaches.

Interviews were also conducted with two young men who acted as "controllers" or "pimps" for female sex workers in sex work areas of Santo Domingo. These are not necessarily bisexual, but they generally seem to be willing, clandestinely, to accept invitations from men considered to be homosexuals, who offer them money in exchange for sexual intercourse. They were aged 15 and 22 and had had their sexual initiation at the ages of 13 and 14, respectively. The younger was in the fifth grade of primary school, and the elder was in the second year of the baccalaureate. Neither of them was employed, and their financial situation was "all right" in the first case and "wobbly" in the second.

The "sanky-pankies" knew between one and four people who were HIV-positive or had AIDS in their communities. They thought that AIDS "is kept quiet, but there are a lot of cases". The controllers said that they knew of three infected women on their territory at that time.

The "sanky-pankies" would tell their children, male or female "not to go picking up people on the street, to protect themselves". The controllers would teach them how to use condoms and tell them to make sure they knew who they were going to sleep with. One of them said: "I would advise them that hanging around on the street leads nowhere."

Regarding the lifestyle of the "sanky-pankies", the youngest remarked that "I get on fine with everybody, I'm all right", while the other said: "people always talk. I don't take any notice of people. They tell you you're going to get AIDS, but I take care of myself. I have to sort it out for myself. As long as I look after myself, I don't need to worry about *it*". The controllers, for their part, stated that "people tell me to sort things out however I want, but not to take what isn't mine (not to steal). (Others tell me that) I have to change, start working, because you can't live off things that are so dangerous ... Around here you do survive off that, and nobody tries to lead anybody else's life".

Regarding female sex work, the "sankies" thought that "they have another life" and that "that's fine". The controllers, meanwhile, disagreed among themselves: "It's all right in a way, because there's not much work around," said one, while the other said he found it "very bad ... if a woman is healthy she can do some other kind of work".

While the youngest "sanky" said that working as a "gigolo" (living off tourists) "is normal", the other said that "you hardly see that here, that's with women tourists and I don't screw with those people. I'm not interested". Both controllers said that living off women "is bad. A man should work", even though neither of them was doing so.

Concerning sexual relations with men for money, the “sanky-pankies” said that “I’m not bothered” and “that’s fine ... if I’m going to earn 500 pesos with some man for a while ... then I’ll go ahead”. Both controllers, however, said that this type of transaction “is bad ... and it’s worse” than the other two kinds of sex work.

One of the “sankies” gave it as his opinion that “condoms are being used more now”, but the other believed that there had been no change at all, since “from what I can see, the lifestyle has stayed the same”. The controllers believed that condoms were being used more.

As a condition for having sexual relations, the older “sanky” said “a couple of jars (of rum), a couple of pesos”. The controllers spoke of the need for love and for condom use. The younger “sanky” said that using a condom “is safest”, while the other said that he “would have to see who with”. One controller said that unless he put one on “I hold back, I don’t start anything”, and the other agreed with this. While some agreed that they ought to be using a condom with their steady partners (even if they were not doing so), others said that they wouldn’t use condoms with them.

In the event that their partners proved to be HIV-positive, the elder “sanky” said: “I would steer clear of them, because then they infect you,” perhaps because he was homosexual. The younger said that he wouldn’t do anything, just “carry on quietly until the time came to die”. The controllers had a similar attitude: “I would have the tests done, things would stay the same with her, but I wouldn’t make an issue of it, what would be the point?” and “Resign myself”.

They suggested that there should be local plans for “providing free testing for anyone who wants it; they should come and make people aware of it; the Government should help people who get this illness; they should get some people to carry out checks”. One of them finished his interview by saying: “All anyone talks about here are problems and disputes.”

The first of the “sanky-pankies” related the story of a woman sex worker “who did her stuff on the beach”, mainly with tourists. She was a distant friend of his, and had died of AIDS. She was 30 and was a single mother with two children.

The family had known about it for a long time. People said in the neighbourhood that she had AIDS. I was told I ought to keep away from her. I kept away. I kept on nodding terms as always. She lived in another neighbourhood. They deserted her.

The other “sanky-panky” told the story of another female sex worker, now deceased, who had worked in discotheques and on tourist beaches. She was a friend of his and her partner was also a friend. She was 26, had got up to the first year of the baccaalaureate, and was childless. Her financial situation was “very bad”. She lived on a plot close to the beach.

The family were sad, they cried a lot, but they didn’t throw her out. They didn’t let on that it was AIDS; they said she had anaemia. That was really bad. I talked to some boys and to a neighbour, they said that she was thin, that she looked very odd, that she looked as if she had AIDS. They told me to steer clear of her. I treated her virtually the same as always, although I was afraid. They’re poor. She kept the family, but after she fell ill things got worse. Her mother looked after her. One sister helped her, but she concentrated more on the housework. One boy did the errands. I spoke to her mother, but the people who helped her most were the ones from the church. The neighbours grumbled, but they always visited her, especially the Evangelicals. I didn’t hear about any other group except the church.

The 15-year-old “controller” spoke of the case of a sex worker (street girl) with AIDS, a friend of his, and still alive. She was 16; he didn’t know what her education had been. She

was single, without children. Her financial situation was bad, and he didn't know what neighbourhood she lived in. She had been abandoned in the park where she worked, and she was refusing to go back to her family.

They despised her. They came to look for her (in the park) and she didn't want to leave. They haven't said anything, so as not to depress her. I don't talk about 'it', I don't talk about her, but I warn my friends and the women not to get ill. They didn't tell me anything about 'it'. I've carried on treating her the same. The women she worked with cleared off. They deserted her. The illness has affected her a lot; her situation's worse. We tell her she should go to her family. Some people from the television did a report on her. I haven't seen any sign of them helping her. She's been admitted to hospital loads of times, but then she leaves.

The 22-year-old "controller" spoke about a bisexual friend who had died of AIDS. He was 35, the "controller" did not know anything about his education, and he lived with a travelling sex worker who was infected with HIV. He had previously had two children by another woman from the interior of the country. He worked somewhere official. His financial situation was "comfortable" and he lived in a lower middle class neighbourhood.

His relatives didn't show any reaction at all, because they knew the life he was leading, and they were expecting it. They said he had something wrong with one of his lungs. On the one hand I think it's good that they said that, but on the other I think it's bad. I treated him the same as a healthy person, better than the way we got on when he was healthy. Almost all the women bought him his medicines and his balanced diet. His woman knew what he had. They say that she infected him. She took the test so as to travel, and they sent her back. The neighbours behaved better. They were shocked, but they always visited him ... they took him this and that. We always went and talked to them. No group helped him that I know of.

Agents of the security forces (police and soldiers)

Four security force agents aged 22-24 were interviewed. By and large, these people belong to the same strata of the social classes most usually identified with street culture, and they could be defined as "observers" of that culture, if not "actors". Their educational level ranged from fifth-year primary to first-year baccalaureate. Two of them were single, without children; two were cohabiting with women, and of these one had no children, while the other had four. Their financial situation ranged from "bad" to "good". They lived in poor neighbourhoods in Santo Domingo.

They believed that there were many scattered cases of AIDS, that there was "a lot of talk, it's putting paid to everybody". They knew between two and 10 people who were HIV-positive or had AIDS, some of them alive, others dead. They would tell their male children to look after themselves well, to use condoms, "not to pick women up in the street". They would advise their daughters to "make a home early ... to educate themselves and go to bed early ... not to go around in the streets".

Regarding female sex work, two were against it ("They're very low people ... I was going to sleep with a woman once ... and she was sick") and two didn't condemn it ("It's understandable, given the unemployment there is, and how tight things are economically"; "They should look after themselves"). On the subject of gigolos, two of them said that they were "not going down the right road" and were not "real men". The others saw it as justifiable, provided "they protect the women". Opinions about sexual relations between men were equally divided between those who said that those who engaged in them were "harmful, low, promiscuous and dirty" and those who said "they should both protect themselves".

The more conservative ones said that “the young ones, the 13- to 25-year-olds, don’t look after themselves ... licentiousness is rife among the young”, while the more liberal ones said that “sex is more selective now”. As preconditions for having sexual relations with a woman they named “getting to know each other first, using condoms, and going to the doctor for examinations”. All four rejected the idea of using condoms with their steady partners, however, “unless something is suspected”.

If their partners proved to be HIV positive, one would have himself tested “to see if I had it”, another would carry on with his partner, a third “would convert to religion, because harming her wouldn’t achieve anything”, and the fourth said he would kill her. They suggested “rounding up the loose women from the streets, isolating the people affected, putting them in a home, not letting them mix with everybody else ... so that the people who’ve got it don’t contaminate the rest”. One suggested increasing prevention work among the young and adolescents.

The first security force agent, aged 22, knew a neighbour and her small daughter who had both died of AIDS. The mother was 27, her schooling was unknown, she had occupied herself with household tasks and remained single. Her financial situation was very precarious, and she lived in a deprived neighbourhood.

Her family tried to conceal the illness by saying she had a problem with her kidneys. They lied, they should have told the truth. She went to clinics and hospitals but they never said it was AIDS. We didn’t know it was AIDS, but we found out at the end. Among friends, we talked about how close death was. They told me to help her with money. We knew each other, not very well. I felt sorry about her case. A small daughter was infected, and died a week after her mother. The other children were negative. The children in the neighbourhood played with them; they didn’t know about the mother’s illness. She wasn’t bedridden for long. When she fell ill, she died. The neighbourhood council and those of us who lived in the area raised money for the funeral. The whole neighbourhood contributed.

The second security force agent, who was also 22, spoke of a neighbour who had died of AIDS. He was 26, had reached the first year of the baccalaureate and was married with one son. He was a street seller, his financial situation was middling, and he lived in a deprived neighbourhood.

The doctors telephoned his father, but he never believed it. They wouldn’t accept reality. The family left the country. They deserted him, they went abroad. He couldn’t leave because he was positive. They said that it was another illness, that it was tuberculosis. They shouldn’t have concealed it. I spoke to someone of the family about what the doctor had admitted. They told me to trust him. The father has the boy, they did the tests on him and he came out negative. The neighbours treated him badly, because he was unpleasant ... but they eventually helped with money. No group helped him.

The third security force agent, aged 23, spoke about an acquaintance, now dead from AIDS, who “dried up slowly”. He was 30 and had two children. He did not work but depended on his family, and lived in a rural location in the interior of the country.

They didn’t say anything, they kept it well hidden. That was wrong. I felt very sorry for him. I spoke with a friend, we agreed we had to take care. They told me to be careful about touching him. I didn’t see him for some months. The family helped with medicines and money ... they have money in the countryside. His mother helped him by looking after him, his brothers with money.

The fourth security force agent, aged 24, told the story of a female friend and neighbour who had died of AIDS. She was between 35 and 38, schooling unknown, cohabiting and with two children. She was a sex worker in a cabaret. Her financial situation was “very bad” and she lived in a poor neighbourhood.

They sacked her from her job. The other women who worked there didn't visit her. She lived with a sister and they moved her to her mother's, to hide her. They said she had a kidney infection. That was very wrong; they should have left her in the neighbourhood. Anyway it came out ... people knew. I spoke to friends and neighbours, told them to take care. They told me 'Don't go with her'. I felt very bad about it. They did blood tests on the children. They're normal, fine. The children were all playing with other children, normal. Her brothers helped her with food and medicines. The neighbours visited and helped out with food. Nothing changed. She took to her bed and lasted a fortnight. The committee of a political party donated the coffin.

Street boys ("palomos")

Interviews were held with three young men who carried out informal work as bootblacks in a sex trade district of Santo Domingo (Enriquillo park). They spent the whole day there, made friends and did "errands" for sex workers, controllers and customers and, for cultural reasons, they had probably played or would play one or more of these roles as they grew up.

The youths were aged from 15 to 17, and their sexual initiation had taken place when they were 12 to 14. In educational level, they ranged from the seventh grade of intermediate school to the baccalaureate. The youngest already had a steady partner, but none of the three had had children. Their financial situation was very precarious. Two of them lived in the vicinity of the park and one of them in a poor neighbourhood nearby.

All three agreed that there were a lot of AIDS cases where they worked. Young as he was, one of them said: "I've seen several people die." They mentioned between one and four cases of people that they knew with HIV or AIDS. If they had a male child, they would tell him "to look after himself, by using condoms", while a girl would be advised "to insist that men use condoms". Regarding female sex work, one said "I don't think much of it", but the others said that "it's okay, they need to help themselves, it's a job ... if they don't go around infecting anybody ... It's wrong if they've got AIDS and they go around doing it". Two disapproved of "living off women" ("it's bad, you should work") while one thought it was "all right" to do this. All three displayed strong homophobia ("that's serious ... it's terrible ... it's not written in the Bible").

They noticed that "a lot of people have left the 'scene'", there was "a lot of condom use", and around half the people "are taking AIDS into account". As preconditions for sexual relations, they mentioned hygiene ("It should be someone clean", "If she's got tooth cavities, I won't live with her") and condom use. One of them, however, said that if he had known the woman for some time, he wouldn't use a condom. All three said that they didn't use condoms with their steady partners, "because she's my woman ... if she's my wife ... we trust each other".

If their partners turned out to be HIV-positive, all three said they would do "something horrible, I'd kill her. We'd both be dead ... I'd shoot her through the head", although one seemed to think better of it and added: "Or take care not to infect anybody else." They thought that the Public Health authorities should "pick up all the street women ... from the Bolita del Mundo, the Sarasota, the Duarte ... get the vagrants off the street ... put a fence round them and machine-gun the lot of them".

The first street boy (bootblack), aged 15, spoke about a female neighbour who had died of AIDS. She was 21, schooling unknown, unmarried and childless. She was employed as a domestic worker. Her financial situation was "very bad" and she lived in a poor neighbourhood.

Her family reacted by calling the doctor and being kind to her. They said she was suffering from ulcers. They hid the disease. I and some other shoe-shiners talked about 'getting off the street'. My family told me not to visit that house for the time being ... but I went there more to learn about the disease. She was working in a family home. They sacked her. They had a lot of expenses. Her brothers helped with money. The neighbourhood committee helped with a collection. She was admitted twice to the Padre Billini hospital. The neighbours visited her and took her fruit juice.

The second bootblack, aged 17, spoke of a neighbour who was a distant friend of his, and who had died of AIDS. He "lived with a street woman" (sex worker), was 23, and had got his baccalaureate. He was "a pimp and a vagrant, he drank". He had a child by another woman. His financial situation was "very bad", and he lived in a poor neighbourhood. He died in the countryside in the interior.

His family left him to the streets and didn't know what he was doing. He never went to see them. The streets were his life. When it came out that he was ill, the woman disappeared. I spoke to my friends in the park. I deserted him, I stopped sitting on his bed. My brother told me to leave the streets. The first woman and the daughter went to the doctor ... but they were negative. It had been some time since they'd split up. She married someone else. They told her daughter 'your father died of AIDS'. He was never a father to her. They insulted him in the neighbourhood. When he came round here he was at death's door. His family lived in the countryside, and he moved there. He went to his mother's house to die. He wasn't ill in bed for long; he died all of a sudden.

The third bootblack, who was also 17, told the story of a female neighbour who had died of AIDS. She was single and childless, age unknown. She worked in a free-trade zone and her financial situation was "critical". She lived in a poor neighbourhood.

Her family said she had leukaemia, they didn't want to tell the truth. I spoke with some other shoe-shiners. They told me to be very careful if she fell in love with me. I was scared. She was kind and sincere. I saw five or six friends taking presents round to her. Her family spent a lot of money. I felt really sorry for her. The people who helped her most were one brother who was a soldier, a friend and a godfather. They had her admitted to the central Armed Forces hospital and the Luis Aybar.

Female Sex Workers

Interviews were held with eight young women who carried out sex work. The results are summarized below. The four younger sex workers were aged from 16 to 18. Those who worked on the streets had had their sexual initiation between the ages of 9 and 11, those in the brothels between the ages of 14 and 15. They regarded the AIDS situation as "dangerous", as "a lot of people are dying". They knew between one and four people with AIDS. The four older sex workers were aged from 22 to 26, and had had their initiation between the ages of 11 and 17. They knew from two to four people who had died of AIDS. Women employed in brothels tended to hide the nature of the work they did from their families.

As regards what they would tell their male children about AIDS, the replies varied from persuasion and prevention ("trust me, protect yourself with a condom, take the test") to restrictions that were inconsistent with their own work ("be careful of the streets, don't pick up street women"). They would give similar instructions to their daughters ("she should use a condom, protect herself properly, know how to look after herself, she shouldn't let herself be taken in by promises, she should avoid the street, she should marry a man who's for life").

They tended to justify female sex work as a way of earning a living: "It's not good, but I couldn't finish my studies." The others said: "If I don't work, nobody's going to give it to me for free ... everyone gets by the best they can ... only you should take good care of yourself". For a man to live off women, however, was somewhat frowned upon: "I'm against

it, because a man can work out there ... it's men that are supposed to give money to women ... they shouldn't be in society, because they're the ones they call pimps." Others, however, said that "they bring in money as well" and that "he should put on a condom and always protect himself". To a man who "did it" with another man they would say "don't do it, it's a bad thing to do ... men weren't made to do it with other men, but with women", although they realized that "there are a lot who do it because they like it ... there are some who are 'born to it' while others aren't. I don't criticize that".

On the subject of changes in sexual behaviour, they said that men "go out less" and that previously customers had done it without protection, but that now most of them used a condom, or masturbated while performing oral sex. Some were fearful, others were not. When having sexual intercourse with customers the women insisted on condoms and refused to deep kiss, although some "do it without a condom". Some always used condoms with customers, but not with their husbands (steady partners). Others believed it was better to use condoms in all cases "because he might have other girls", "nobody knows what he gets up to out there" and "I don't trust anybody".

They were asked what they thought they would do if their partner had AIDS. Two would simply take the HIV test to see if they were infected, three said they would leave him or kill him and themselves, and three would reconcile themselves to it, accept it and support him. They thought the Public Health authorities should help the street boys and women sex workers, carry out HIV testing in the brothels and set up apartment-hotel type care centres for people with AIDS where their families could go to visit them.

Cases reported by women

Minors

The first minor, a sex worker in the street, had had an adolescent male friend (a "palomito"), now deceased. He had been single, childless and well-off financially, but had lived by stealing things in the street.

His family didn't support him at first, but they took him into the house in the end. They had to support him until he died. The family said he had AIDS. I spoke to a sister and two or three shoe-shiners that were around. If I had money I gave him five or ten pesos. We used to go and see him in his house. We took him money, eight "palomitos" and five "palomitas" from the bridge and the park. We got very sad when we visited him.

The second minor from the street knew a 30-year-old woman, a sex worker who had since died. She had the baccalaureate, cohabited, and had two children who went to their grandmother when she died.

Nobody wants to have that disease. She didn't go looking for the disease. Her family pretended she didn't have AIDS; they said it was another illness. I spoke to my family, my cousin, my friend. I was afraid because I was on the streets and I could put myself in her place. My cousin told me not to drink out of her glass because I could get AIDS. She was a bit distant with the woman. People felt sorry for her ... after they saw her on the point of death. She was supported by people from the church, her mother and her boyfriend.

The case that was closest to the first under-age sex worker from the brothel was a 33-year-old male friend, a lawyer and businessman with two children, who had since died.

His mother had a fit when she found out. I felt terrible, because her son was her only hope. The family didn't say anything, but a friend of mine ... told me what they were thinking. She told me not to show

them that I felt disgusted, to carry on as before. I stopped speaking to him, and went a long time without seeing him. His wife stayed with the children. His brother took care of the business. An employee of his asked me if I was in love with him. His business partner behaved well. The people from the church ... washed him - a lot of women, no men.

The second under-age brothel worker had known a 40-year-old man with two children, now deceased, who had owned a grocery business.

He was ill, but they didn't let on that it was AIDS. I spoke to my sister and she told me to keep my distance from him. I kept away. The neighbours treated him the same as ever, because he concealed it, but they kept away from him once they knew. The sales of the business dropped. Then they felt sorry for him. I went just once, and my mother told me to keep my distance. I didn't go near him. His family helped him, the women more than the men. His mother has the boy. Some neighbours went to see him in hospital, and came back saying: He's dying!

Adults

The first adult female sex worker, who worked on the streets, spoke of a neighbour who had died of AIDS. He had worked on the beach, was badly off, and had a wife and son.

His family concealed the disease ... they said he had leprosy. The neighbours always said he had AIDS. I always went to see him ... I treated him so-so because there are some people you can't trust, because they're devious. The neighbours behaved well, they never turned their backs on him. Some people from the church and some neighbours went to speak to him about hell. A lot of people didn't go near him, because they didn't want to fall ill. Others went and sat on the bed.

The other adult sex worker, who also worked on the streets, told the story of a 23-year-old neighbour, since deceased. She had been married, living with her husband, and childless. She didn't work, and her financial situation was average.

The family had a neighbour of hers arrested, because they thought the woman put a curse on her. They did a news item about it on television, and that was when it came out (that it was AIDS). I wasn't a friend of hers. Then they moved away from the neighbourhood. The last time I saw her she was very thin. After she died I stood by her. I changed her and helped to lay her out.

The first adult brothel worker had known another woman working in the brothel who had died of AIDS. She had had two children, who had gone to her mother.

She always lived with older men because she felt safer that way. When she took to her bed she told her friends to look after themselves. Her family wouldn't admit that it was AIDS. Her mother and friends helped her. Some neighbours found out. After she died, her family said it was AIDS.

The second adult brothel worker talked about the case of a 30-year-old woman, a sex worker and the wife of a man who had died of AIDS. They had both worked in the same brothel.

My friend's husband went a lot to the brothel and said he didn't go with women without a condom. He went into a decline, started changing ... his looks weren't the same. I talked to him about it; I said they shouldn't discriminate against him, that he should feel he had a right to live. It was very sad to know that he was dying, because he hadn't protected himself. Only a disc-jockey friend went to see him ... The neighbours behaved well, they always went to visit him, but some to see him and others to stir up trouble. It grieves me to see how other people reject someone who's infected. It pains me to see the poor orphan children.

People and families affected by HIV/AIDS

A series of semi-structured interviews was held with members of couples of whom one or both had HIV (HIV-positive or negative wives of living HIV-positive men, HIV-negative husbands of living HIV-positive women), mothers of people who had died of AIDS and neighbours of HIV-positive people, both living and dead.

Couples where both are HIV-positive

The two HIV-positive women with infected partners were aged 39 and 41 and supported themselves by working, one as a domestic worker and the other as a craftswoman. They had completed between five and eight years of schooling, they had four or five children, their financial situation was between precarious and “stable”, and they lived in poor neighbourhoods. Both their husbands, the first of whom was 66 while the age of the other was unknown, were working at the time they were diagnosed.

The first husband was a porter in a public hospital. He took the HIV test for a surgical procedure, and it came out positive. A nurse in the hospital broke her obligation of confidentiality and revealed the diagnosis to the wife, without either informed consent or any special training for this. A doctor in the hospital offered the husband support, but he did not keep the appointments, and at the time of the interview he was still refusing to go to the doctor. The wife said that he “went from sick leave to sick leave until they dismissed him” from the hospital, which meant that all they had was her small income as a domestic worker.

The other husband was a self-employed building worker. A small daughter of this couple’s was also tested, but came out negative. At the time of the study, the wife had a kidney infection and a tumour in one ovary, and they were both being treated for pulmonary tuberculosis. Illness had affected them financially.

The first wife said that when she received the diagnosis she felt frustrated. Her sexual relations “cooled off a bit, but then everything carried on the same”. Both families, starting with the brothers and sisters, were told “the truth”, i.e. that they were HIV-positive. The families of both had helped them “psychologically”, but not financially. They did not have enough money for the medicines they needed. Nonetheless, they felt they were coping with the disease adequately.

The second wife separated from her husband for two years when she heard the diagnosis, but they were then reconciled. At that time she did not talk about her situation to anybody. Later, they told their families that she had “cancer”, but they did not know that both of them had AIDS. She said that she felt fear when she had sexual intercourse, despite being infected and using a condom. Her children knew that she was positive, and their mother sensed that they had changed, as they showed a mixture of defiance and fear.

The first wife said that the neighbours knew about her infection and had reacted “well” towards her, without giving many details. They did not know of any self-help groups for HIV-positive people at the time of the study. The second wife said that the neighbours did not know they were infected. Nonetheless, they had received support from the Dominican Red Cross and the Santo Domingo Dermatological Institute. They were currently attending the Santo Domingo Health Centre. They also belonged to Propuesta de Apoyo a la Vida and another group for people living with HIV/AIDS in the parish of Santísima Trinidad.

If she brought up a male child, the second wife would simply tell him “to look after himself, by using a condom”. She would tell a girl to take “care with men, because women can’t let themselves be used by them”, probably alluding to her own experience.

Couples where one partner is HIV-positive and the other not

HIV-negative women, HIV-positive men

The HIV-negative women in the first two couples were aged 28 and 34 respectively, each had one son, and both lived in poor neighbourhoods. The psychologists who gave them the negative results told the first “to look after herself” and both to give their husbands “plenty of love and affection”. The first was working as a secretary, and was in a precarious financial situation. She said that the illness had had major financial repercussions for them. The second wife was a university student, did not work, and had a “varying” financial situation.

The husbands were aged 33 and 41 respectively, and were not working. One had his baccalaureate and had worked in a private electricity company that supported him and “kept the secret”. He was being treated for herpes and toxoplasmosis. The other was a university student and worked in engineering. When he had asked for medical treatment it had been provided in the normal way, as there was no suspicion that he was HIV-positive. He had suffered only from allergies and chickenpox.

Both women said they were frightened that their small children might be infected, even though they themselves were negative. The first said: “I don’t want to put him through it (the HIV test); I’m afraid of the results being positive. I’m so worried by the situation.” Both were aware that a pregnancy would be highly risky for them: “I’m frightened when I think I could end up pregnant,” said the first, which appears to suggest that unprotected intercourse was taking place. She added that she was fearful that her husband might infect her, so that their sexual relations were less frequent and of lower quality than before: “We got on badly before, and now we have intercourse less often and the situation has got worse.”

The second said that “it’s out of the question (to get pregnant), because I would be exposing myself to the risk of disease, and the baby, too”. Both couples had concealed the infection from the women’s families (perhaps under pressure from the husbands and their families), which meant their fathers, mothers, brothers and sisters were ignorant of the situation they were going through. Taken together, these findings could be evidence of gender differences in the power structure of our society.

The first wife said her husband had told her he was HIV-positive, “although she already suspected it” from the symptoms. Members of his family knew about it before she did. They consoled him. Nonetheless, only one sister and an aunt of the husband’s had helped them. The other relatives did not know and seemed to have a difficult relationship with him: “His family drive him to despair; they can’t tolerate his character.”

The second wife said that her husband had had the HIV test done because he was to have minor surgery. The doctor who did the operation, a friend of his, did not reveal the positive diagnosis to his colleagues in the surgery. At that point, she said, the emotional state of the household “deteriorated”, but then it improved. They used condoms in sexual intercourse. Only his family knew about his condition: “We told the family the truth; his parents treat him the same as before ... they come and keep him company when they know

he's feeling bad, and they give him emotional support." Both women said that, in general, their friends and neighbours did not know about their husbands' condition. They had also had to conceal the illness, the first saying that her husband had "a tumour and a parasite in the brain", while the second said hers had "haemorrhoids".

The first wife said that "only a few of his friends know about it; they've carried on treating him the same, and they've helped him". Others (who perhaps suspected it or knew too) had stopped visiting him, according to her, because "they felt so sorry and upset" about his condition (herpes, toxoplasmosis). They always said they would come to the house, but they never did. Her husband had received attention in the Salvador Gautier hospital and was a member of the Dermatological Institute self-help group. The second wife said that her husband was going to psychotherapy sessions and belonged to Propuesta de Apoyo a la Vida.

The first wife would tell a male child "to look at what's happened to his father". She would tell a girl, when she had a boyfriend and decided to have sexual relations, to ask him to get "the tests" done. She also added, probably alluding to her own experience, that "those who are ill should be healthy in their hearts, they shouldn't try to infect other people". The second wife would tell a male child to use condoms, and would tell a daughter to "take care with her partner".

HIV-positive women, HIV-negative men

The interviews carried out with the two HIV-negative men with HIV-positive wives revealed that they had not completed primary schooling, were working, one as a carpenter and the other in a furniture factory, were in a "not very good" and "stable" financial situation respectively, and lived in poor neighbourhoods. Their wives were 23 and 29, with three and two children respectively, and had had similar schooling to that of their husbands. They were not working.

The first wife had found out she was HIV-positive when she had had an HIV test in connection with her last pregnancy. She was being treated for pulmonary tuberculosis. They had not had the baby tested, so they did not know whether it was positive or not. The second woman, according to her husband, had had the tests done (probably because of the symptoms) and "had 'it'" (HIV). She was currently suffering from a vaginal infection and herpes zoster. The two daughters had had the HIV test, and the younger had proved to be HIV-positive.

The first husband said that after they had learned of the diagnosis, "everything went on as before", he hadn't talked to anyone about the case, and he didn't know how they had treated her in hospital, as he had been working on those occasions. "She told her mother and her family, and they behave well towards her, her mother, sisters and friends help out ... Nobody else knows." The second husband also said that "everything carried on fine, the same". He did not speak to anyone either, and he thought she was getting good treatment in the hospital. The situation had not affected their sexual relations, "only now we take care", he said. "She took precautions" (to avoid becoming pregnant).

The first husband said that "we didn't tell people anything ... they don't know ... the neighbours don't know". Then he said that "they treat her well in the health centres", saying finally that the situation "is terrible for me". The second husband said that his wife went to the meetings of the Santísima Trinidad parish self-help group.

The first husband would tell a male child to “look after himself, use a condom”. He would tell a daughter “to have just one man, and make sure that man uses a condom” (probably implying extramarital relations).

Mothers of people who have died of AIDS

Interviews were held with two mothers (aged 57 and 45 respectively) of HIV-positive people who had died (a 26-year-old male and a 33-year-old only daughter). Both had a minimal level of schooling, they were not working, and they lived in poor neighbourhoods. The first had seven children. Her deceased son had worked in a telephone company, where they gave him the HIV test. He turned out to be positive, and they dismissed him. The other mother was unmarried and was in a “middling” financial position. Her deceased daughter was married. Her husband had died of AIDS, leaving three grown-up HIV-negative children. She had worked in a free-trade zone, where they had diagnosed the infection and then dismissed her.

The young man’s brothers turned him out of the house when they found out about the diagnosis. He had a partner when he died, an HIV-positive woman he had met at a self-help meeting. They had married two years after meeting. One sister, his wife, a sister-in-law and his mother’s brothers helped him. One uncle helped with money. The mother said she was grateful to the family and neighbours for the treatment they had received. She said they had done everything possible to keep him healthy. When he died, they gave away his belongings.

The other mother said that to start with she had felt “mortified”, but then she faced the illness calmly. She said, however, that “just thinking about it gives me gooseflesh”. At the health centres, she said, they treated her daughter well, “they treated her with love”. One sister “who saw her born and die” was her main carer. “We women bathed her and cared for her, the men helped to carry her.” Her son kept the personal effects, the clothes were placed in the coffin, she herself kept some items as keepsakes, and the rest was thrown away.

Both mothers said that their friends and neighbours had been told that it was AIDS “because they would have found out anyway”, “because it was obvious and it couldn’t be kept quiet”. The first mother said that they received support from the National Laboratory and the Institute of Human Sexuality. At the Santo Domingo Health Centre they gave “good care”. At the Padre Billini hospital, however, the care was “not good at all”. The second mother said that her daughter’s work colleagues went to see her at home. They used private clinics, not public hospitals, to care for her daughter.

Neighbours of HIV-positive people

Interviews were held with two people, a woman and a man in a precarious financial situation, who lived in a poor neighbourhood. They were neighbours of an HIV-positive woman and an HIV-positive man, respectively.

The woman, who was 43, had intermediate schooling and four children, and was a seamstress. Her HIV-positive neighbour had died at the age of 32. She had left orphaned children, who were HIV-negative. When she was alive she had not worked, her financial situation was “bad”, and her husband was HIV-positive and still alive at the time of the interview. He was a public sector employee, and was dismissed when the diagnosis came out.

The man, who was 68, had primary schooling and six children. He was a salesman. His HIV-positive neighbour, who was 33, cohabited and was childless. His schooling was unknown, he made a living by washing cars, and his financial situation was “bad”.

The neighbour of the HIV-positive woman found out about the infection from another neighbour, but she did not speak to anybody about it, or seek help. “Everything carried on the same with her”, and afterwards she felt “kinder towards her or sorrier for her”. The children were tested and came out negative. Both in the family and in the neighbourhood, the illness was faced with calm and sadness. “They didn’t give any explanation to anybody.” She was treated in the Moscoso Puello hospital and in the Salvador Gautier hospital.

The neighbour of the HIV-positive man said that the sufferer himself had told everybody in the neighbourhood. “Everything went on the same, his partner is HIV-positive just like him. He got together with her after he fell ill ... He told the truth to his family and the neighbourhood. The family helps out with food and housework, and they look after him. The men come up with money.” He was treated in the Padre Billini hospital. The sickness affected him greatly, because “they’ve got no savings, and when a person’s ill that’s a worry”.

People close to the HIV-positive woman “told someone that she had AIDS, and the news spread by word of mouth”. To start with, the other neighbours did not let her children go around with other children from the neighbourhood, but “afterwards it was different”. The two women were good friends right up to the end. “I helped out when they needed me,” she said. As to the HIV-positive husband, “the people who rejected him before treat him normally now. He gets together with groups and talks”.

The other neighbour said that the HIV-positive couple “get support at a church they go to. If a bit of money’s needed, they collect it and give it to them. They give them medicine and help them by bringing things that they need”.

The woman neighbour interviewed said that if she were to bring up a boy she would tell him “not to walk the streets, and not to get carried away by pretty women; that AIDS doesn’t show up in someone’s face; that he should look after himself”. To her daughter, “I talk about her schoolwork, I never talk about ‘it’. When we all get together to talk about these things, she joins in, but that’s all.”

People affected indirectly by AIDS

Shamans (folk healers or “curiosos”)

Interviews were held with three shamans (folk healers or “curiosos”) who had had some experience with treating HIV-positive people. The first respondent was female, aged 56, and worked in Los Mina Norte. The second was also female, described herself as a “spiritual psychic” (she reads French and Spanish cards), was 46, and had her practice in Herrera. The third was male, 74 years old, and had had 20 years’ experience. He had reached the third year of primary school, was single, came from the poorer class, and gave his consultations in Villa Consuelo.

According to the assessments of these respondents, “AIDS is very widespread in these neighbourhoods”. All three said that they had received AIDS sufferers in their practices. The knowledge that these three people had about AIDS seemed to be quite sound. They knew that

HIV was transmitted by sexual contact, in the semen, by blood transfusions and by contact with cuts. One of the women said, "before, I was afraid of being infected when I treated people with AIDS. Not any more. It doesn't worry me." The man added, "I haven't felt any concern about being infected by AIDS ... I don't take any special precautions; that's not how it's caught. Also, the important thing is not me, it's the Mystery, the Horse that mounts up to my head," referring to the state of trance in which he worked.

The other woman, however, said that "if someone with AIDS comes to the altar, you take your precautions, even if you don't show it. You make a note of the glass you use if you give them water, and you clean the bathroom, if they use it." These precautions seem to be part of traditional conceptions about hygiene, probably inherited from the prophylactic measures taken for tuberculosis and syphilis. Two of the three people interviewed said they knew they could not cure somebody with AIDS, and they did not expect anyone to think they could. "AIDS is not cured at the altar. Only God can cure a person," said one woman. The eldest, however, said that he "had not formed an opinion" as to whether it could be cured or not, and he did "not know how to do it, since that is something that only the Mystery of the Night knows".

The two shamans who appeared to be most experienced in dealing with HIV-positive people were at one in saying that patients arrived in a state of anxiety and desperation. "When people with AIDS come to my altar, the question they always ask is 'How much life do you see left for me?'. Of course, you're never going to tell them that they're going to last three or four months, even if you see it in the cards or the glass ... You tell them they're going to get better, even if they don't have long to live."

They said that their task was to "calm down" sufferers emotionally, providing them with support, advice, and greater calm and composure. They stressed to them "that they should keep themselves busy and occupied, not think about death and make their peace with God". They sent them to church and "to the countryside ... to rest their body in the home of some relative ... to await death there". This is a fundamental part of the fatalism that unfortunately has accompanied AIDS since the outset. They said that they had prescribed herbal plants such as "cat's claw", a concoction known as *agua de la buena suerte*, natural products, potions and lime tea, a natural relaxant. "They go away calm. I don't lie to them, I just disguise the truth. You can tell their families that they don't have long to live." Both said they felt depressed when they treated AIDS patients, because it was so sad. "I think about my children and my husband, my family ... AIDS breaks up a family. I just think it could happen to me and see myself in that situation. AIDS is not a myth."

Burial workers and layers-out of corpses

Two layers-out were interviewed. One was a pensioner aged 71 who worked in four undertakers' establishments in the upper part of Santo Domingo. The other was 35 and had been working for eight months in an undertaker's in the northern part of central Santo Domingo. Interviews were also held with two masons who carried out burial work, known as "zacatecas". One of them was 35 and had been working on a self-employed basis for 15 years in the Los Mina Norte cemetery, while the other was 42 and had been working for 10 years in the Cristo Rey cemetery as an employee of the city council.

Both layers-out had empirical experience of their trade, meaning that they had not been specially trained for it. One had learnt it in the morgue of a public hospital, and the other from a "master who taught me the main points for making a body 'last'". The first said that

he had “laid out only one body with AIDS, a neighbour, from a family I knew”. The second had laid out six bodies with AIDS. He said he actually preferred them, “because the plump ones (without AIDS) contain liquid ... which is what smells” (while the emaciated and dehydrated body of an AIDS victim does not). To do their work they wore gowns, gloves and masks for health protection. They did not feel that preparing an AIDS victim was anything out of the ordinary. One of them stressed that “hepatitis B is more dangerous than AIDS”.

The burial workers operated alongside other masons from the cemetery, who “carry water and make the niches”. Neither of the two had been trained to carry out his work, but had simply learnt it by watching others and working in cemeteries. They said they kept records of the people buried. In one of the cemeteries, “more than 15 AIDS bodies have been buried” and the foreman “has got landed with burying two or three of them” (probably this work was shared out equally). In the other, “two people who had died of AIDS were buried last week”. They and the other burial workers did not take any special health safety measures. However, magical beliefs about infection appeared to persist with them: “I’m not going to get infected. We don’t touch the body, we keep our hands off it. Their families carry them ... They have to be properly covered. The coffin has to be properly covered.”

High-impact community

In the last three years, there have been public rumours to the effect that a particular *batey* (sugar-growing agricultural colony) in the National District has a high number of AIDS cases. To learn more about the real scale of this phenomenon, a number of visits were made to the community, in the course of which interviews were held with five key respondents: an aged community leader, who was 89, a 51-year-old doctor who ran a rural clinic, the 31-year-old head of the neighbourhood council, a 61-year-old Catholic priest and a 22-year-old leader of the “*motoconchistas*” (motorcycle taxi drivers).

The respondents said that “this is a very poor *batey* ... there are about 20,000 people living here, according to the latest census”. Since very remote times, most of the people in the community have been black. The sugar mill is the source of most employment. The inhabitants live from sugar cane cutting and carting, from small businesses, from motorcycle taxi services and from harvesting lesser crops.

The respondents were united in stating that there was fear of AIDS in the community: “People are on their guard ... People are a bit scared ... People say there is a lot of AIDS here, but we really can’t know ... You don’t see them ... Whenever anyone dies they say it’s from ‘it’, whenever anyone’s thin as well, but they’re rumours ... It’s not true that there’s been an outbreak of AIDS cases here. There’s the odd case spread around different communities. But clusters of cases, no.” The priest said: “Two years ago I said mass for a young man who had died of AIDS. People talked a lot, a lot of things were suggested, there was a bit of a panic. A lot of people attended, they drank coffee and they approached the coffin fearfully.”

Despite these rumours, everyone was also agreed that there had only been three confirmed cases, and they dated back two years. “Then three boys died of breakbone fever, and it was put about that it was AIDS ... there was a tremendous fuss ... but it’s not true. A year ago a young man died and people said it was from AIDS, but it hasn’t been proved.” The head of the neighbourhood council said “I’ve had carriers of the virus pointed out to me, and they’re alive, leading a normal life, and people are saying they’re infected ... they should pick up everyone who’s got this disease to stop them contaminating everybody else.” The *motoconchista* added, however, “I don’t know any families where there are AIDS cases.”

According to the doctor, "people have themselves tested outside the community (for reasons of confidentiality), and it's difficult to quantify them. They move, too; there's constant migration." Others said that "there's still a lot of education needed. People don't see the risk and they have sex without taking the necessary precautions. Most of the young people don't take any notice of the recommendations made by the medical institutions." Despite this, two of the respondents said that "people are looking after themselves".

According to the respondents, there was a neighbourhood council in each district, and women's and youth associations also operated. Nonetheless, they said, "we're not working with the community organizations. Everyone is working on their own".

Different preventive activities were being carried out. The priest was giving talks about AIDS in the parish, and at mass "we ask people to take care of themselves". The doctor maintained that "in the clinic we have a secret record of people showing symptoms of the disease. There are two clinics, a pharmacy used by the poor ... although there's a shortage of medicines ... and they sell cheap condoms. Health workers ... and people from the CEA, supported by the United Nations Population Fund ... give talks ... they distribute pamphlets, hand out condoms and visit people's homes to attend to the women and children." The *motoconchista*, however, said that "the health service is doing very little".

Special Series on HIV/AIDS Prevention and Care: A Cultural Approach

Since the mid-eighties, the fight against HIV/AIDS has gradually mobilized governments, international agencies and non-governmental organizations. However, it became evident that despite massive action to inform the public about the risks, behavioural changes were not occurring as expected. The infection continued to expand rapidly and serious questions began to emerge as to the efficiency of the efforts undertaken in combating the illness. Experience has demonstrated that the HIV/AIDS epidemic is a complex, multifaceted issue that requires close cooperation and therefore multidimensional strategies.

The establishment of the Joint United Nations Programme on HIV/AIDS (UNAIDS) in 1994 initiated a new approach to the prevention and care of this disease. The first requirement stressed was the need for increased coordination between institutions. An emphasis was also made on the need to work on both prevention and treatment while considering the significant social factors involved. As a result UNAIDS was involved in several studies focusing on developing new methodological strategies with which to tackle the issue.

Following a proposal made by UNESCO's Culture Sector to the UNAIDS Programme, on taking a cultural approach to HIV/AIDS prevention and treatment for sustainable development, a joint project "A Cultural Approach to HIV/AIDS: Prevention and Care" was launched in May 1998. The goals were to stimulate thinking and discussion and reconsider existing tools with a cultural approach.

Taking a cultural approach means considering a population's characteristics – including lifestyles and beliefs – as essential references to the creation of action plans. This is indispensable if behaviour patterns are to be changed on a long-term basis, a vital condition for slowing down or for stopping the expansion of the epidemic.

In the first phase of the project (1998–1999) nine country assessments were carried out in three regions: Sub-Saharan Africa (Angola, Malawi, South Africa, Uganda, Zimbabwe), Asia and the Pacific (Thailand and bordering countries) and the Caribbean (Cuba, Dominican Republic, Jamaica). The findings of these studies were discussed in three subregional workshops held in Cuba, Zimbabwe and Thailand, between April and June 1999. All country assessments as well as the proceedings of the workshops are published within the present Special Series of Studies and Reports of the Cultural Policies for Development Unit.