

Situation analysis of discrimination and stigmatization against People Living with HIV/AIDS in West and Central Africa

Ethical and legal considerations



2000-2003 World AIDS Campaign against Stigma and Discrimination



NAP+ West and Central Africa
Network of African People Living with HIV



Joint United Nations Programme on HIV/AIDS
UNAIDS
UNICEF • UNDP • UNFPA • UNDCP
ILO • UNESCO • WHO • WORLD BANK

With the Technical Support of the
UNAIDS Inter-Country Team for West and Central Africa

English version, June 2002
***Situation analysis of discrimination and stigmatization
against People Living with HIV/AIDS in West and Central Africa***

Original version in French, May 2002
***Analyse situationnelle de la discrimination et de la stigmatisation
envers les Personnes Vivant avec le VIH/SIDA en Afrique de l'Ouest et du Centre***

© Joint United Nations Programme on HIV/AIDS (UNAIDS) 2002. All rights reserved.

This publication may be freely reviewed, quoted, reproduced or translated, in part or in full, provided the source is acknowledged. The document may not be sold or used in conjunction with commercial purposes without prior written approval from UNAIDS (contact : UNAIDS Inter-Country Team for West and Central Africa, Abidjan, Côte d'Ivoire).

The views expressed in documents by named authors are solely the responsibility of those authors. The designations employed

and the presentation of the material in this work do not imply the expression of any opinion whatsoever on the part of UNAIDS concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers and boundaries.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by UNAIDS in preference to others of a similar nature that are not mentioned. Errors and omissions expected, the names of proprietary products are distinguished by initial capital letters.

Situation analysis of discrimination and stigmatization against People Living with HIV/AIDS in West and Central Africa

Ethical and legal considerations



2000-2003 World AIDS Campaign against Stigma and Discrimination

Acknowledgements

This situation analysis on discrimination and stigmatization against People Living with HIV/AIDS (PLWHA) in West and Central Africa is the outcome of a partnership between UNAIDS and the Network of African People Living with HIV (NAP+).

The documentation of cases of discrimination and stigmatization was facilitated by PLWHA, their families, NGOs and associations of support and defence of the rights of people infected and affected by the epidemic, who, through their testimonies, enabled us to give a voice and human face to AIDS. May their contribution enlighten us on the social, ethical and legal aspects of the HIV/AIDS epidemic. We are thankful to all of them.

Our thanks go to the Governments of Burkina Faso, Cameroon, Côte d'Ivoire, Gabon, Ghana and Mauritania, UNAIDS Theme Groups and Country Programme Advisers for facilitating the collection of data as well as providing technical support for the conduct of the study.

We also wish to thank Mrs. Marie Louise N'Dala and Mr. François Byabarumwanzi for their assistance in the collection of relevant country data used in the preparation of this report.

Our sincerest thanks to Mrs. Jo Lindor, Painter, for the watercolour illustrations of the case studies.

"A smile, a stretched hand and life starts all over again...."

Jo Lindor, Painter
Abidjan, Côte d'Ivoire

To all those who, in one way or the other, contributed to this study, we express our profound gratitude.

Contents

▶ Acknowledgements _____	2
▶ List of abbreviations/acronyms _____	4
▶ Executive summary _____	5
▶ Methodology _____	7
▶ Definition of concepts _____	8
▶ Introduction _____	9
<i>Violations of the right to employment</i> _____	11
<i>Violations of the right to medical care and medical secrecy</i> _____	15
<i>Research on HIV/AIDS</i> _____	19
<i>Within the family</i> _____	21
<i>Backward cultural practices</i> _____	25
<i>Rejection by close relatives and friends</i> _____	27
<i>Stigmatization in religious circles</i> _____	31
<i>Banking and insurance</i> _____	33
<i>Immigration and travel</i> _____	35
▶ Synthesis _____	37
▶ Conclusion _____	39
▶ Annexes _____	41
<i>Helsinki Declaration</i> _____	41
<i>Dakar Declaration</i> _____	45
<i>Associations of PLWHA</i> _____	46
▶ References _____	48

List of abbreviations/acronyms

ACAFEJ	Association Camerounaise des Femmes Juristes / Association of Women Lawyers in Cameroon
AFASO	Association des Femmes Actives et Solidaires / Association of Active and Supportive Women
AFSU	Association des Frères et Soeurs Unis / Association of United Brothers and Sisters
AGASS	Association Gabonaise d'Assistance et d'action aux Séropositifs et aux Sidéens / Gabonese Association for Support to PLWHA
AIDS	Acquired Immuno-Deficiency Syndrome
ALA VI	Laafi La Vim Association
ARV	Antiretroviral drug
ASA	African Solidarity Association
ATC	Ambulatory Treatment Centre
CAPSDH	Commission Africaine des Promoteurs de la Santé et des Droits de l'Homme / African Commission of Promoters of Health and Human Rights
CEDEP	Centre pour le Développement des Peuples / Centre for the Development of Peoples
CHRAJ	Commission for Human Rights, Administration and Justice
CICDOC	Centre for Information, Counselling and Documentation on AIDS and Tuberculosis
CPA	Country Programme Adviser
FESADE	Femmes, Santé et Développement en Afrique Sub-saharienne / Women, Health and Development in sub-Saharan Africa
GAPS+ PS	Groupe d'Auto-assistance des Personnes vivant avec le VIH/SIDA et de Promotion Sociale / Social Promotion and Self Assistance Group to PLWHA
GTZ	Deutsche Gesellschaft für Technische Zusammenarbeit (German Technical Cooperation Agency)
HIV	Human Immunodeficiency Virus
ICASA	International Conference on AIDS and STDs
ICT	Inter-Country Team
ILO	International Labour Organization
IPC	Initiative Privée et Communautaire de Lutte contre le VIH/SIDA / Private and Community Initiative on HIV/AIDS Control
MASAD	Mission Action SIDA des Assemblées de Dieu / Assemblies of God AIDS Action Mission
MSF	Médecins Sans Frontières
NACC	National AIDS Control Committee
NACP	National AIDS Control Programme
PLWHA	People Living with HIV/AIDS
REDS	Réseau Ethique, Droit et VIH/SIDA / Ethics, Law and HIV/AIDS Network
RIP+	Réseau Ivoirien des Personnes vivant avec le VIH / Ivorian Network of People Living with HIV
ROMASINA	Réseau des ONG Mauritanienne pour la Lutte contre le SIDA / Network of Mauritanian AIDS Control NGOs against AIDS
SONEL	Société Nationale d'Electricité / National Electricity Society
SWAA	Society for Women against AIDS in Africa
UNAIDS	United Nations Joint Programme on HIV/AIDS
WISDOM	Association of People Living with HIV

The situation analysis of discrimination, stigmatization and the ethical and legal aspects in the context of HIV/AIDS in West and Central Africa forms part of the documentation of experiences in the different countries, aimed at providing adequate responses to the HIV/AIDS epidemic.

The objectives of the study, conducted by the UNAIDS Inter-Country Team and the network of people living with HIV/AIDS for West and Central Africa were as follows:

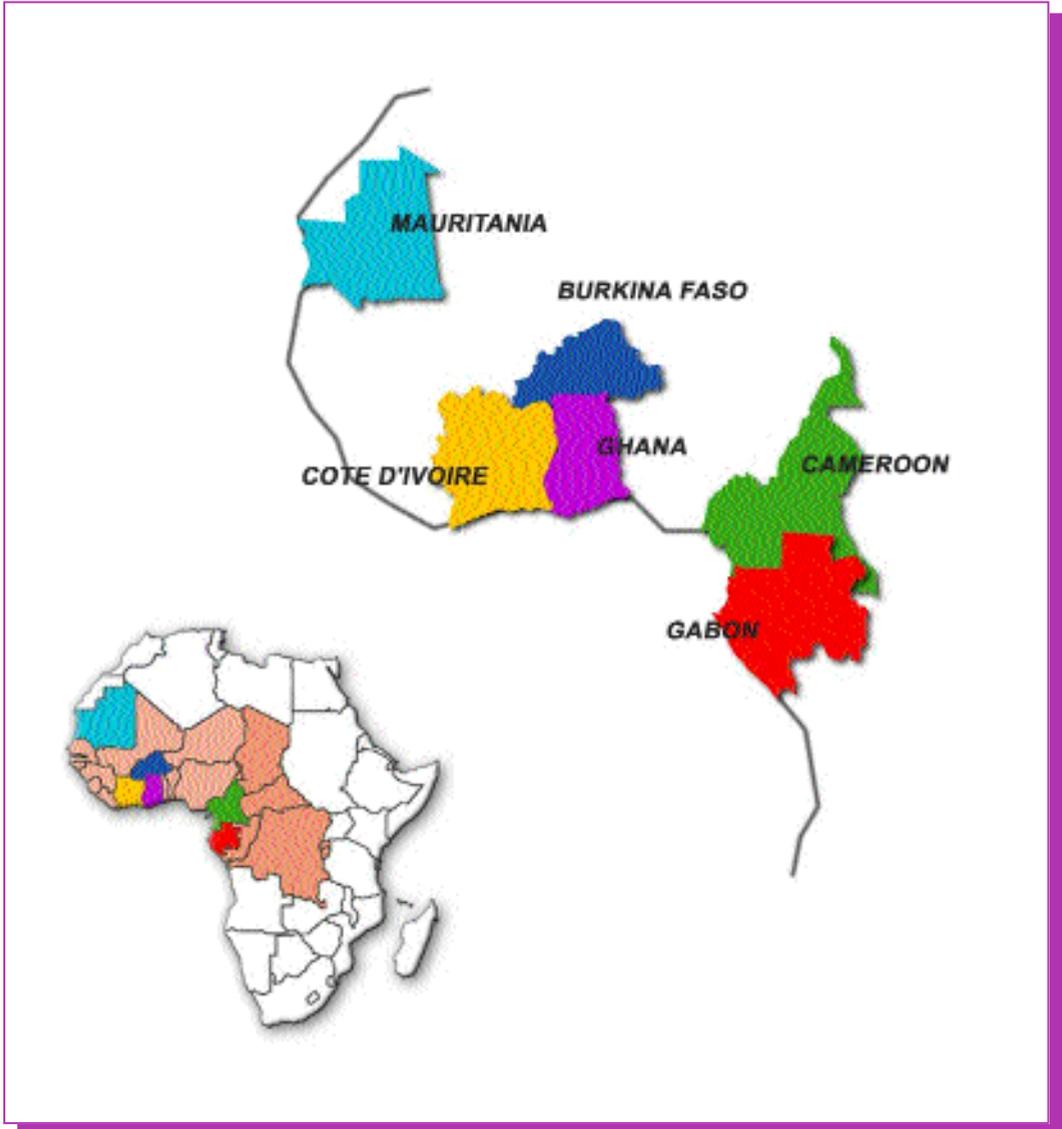
- to identify the factors that promote or impede the welfare of people living with HIV/AIDS in the community;
- to understand the difficulties of involving PLWHA in HIV/AIDS prevention, care and treatment actions;
- to propose solutions for ensuring respect of the rights of PLWHA.

The analysis, conducted in six West and Central African countries, namely Burkina Faso, Cameroon, Côte d'Ivoire, Gabon, Ghana and Mauritania, led to the following observations:

- there are widespread cases of systematic violations of fundamental human rights of people living with HIV, including, among others, violation of medical secrecy, non-respect of private life, violation of the right to employment, violation of the right to health care, violation of the right to accommodation, violation of the right to property, violation of the right to free movement, violation of regulations governing research and therapeutic experiments, violation in the area of insurance and credit, etc;
- systematic testing is widely practised;
- the magnitude of stigmatization and discrimination against PLWHA constitutes the most important factor hampering the involvement of PLWHA in prevention, care and treatment actions in the area of HIV/AIDS control;
- HIV aggravates the woman's social status;
- the medical personnel lack of information and adequate training in the area of HIV/AIDS;
- PLWHA are often powerless in the face of discrimination and stigmatization, because of fear and shame. In fact, without taking into account the other modes of transmission, the society considers PLWHA as being sexually immoral. They cannot even claim their rights in court for fear of being recognized as infected with HIV;
- AIDS heaps opprobrium on the entire family, and, in most cases, the latter rejects the victim;
- rejection, moral judgement, physical and psychological suffering and attack on their dignity sometimes compel PLWHA, including even those who militate in support of associations, to isolate themselves and go into hiding, which seriously hampers the fight against HIV.

To resolve the above issues, the States should adopt measures aimed at:

- promoting and respecting the rights of people living with HIV;
- creating an ethical and legal environment that will encourage PLWHA to come out of their isolation and live positively, to remain responsible and productive members in their community, while strengthening their capacity to assume their duties;
- banning compulsory HIV testing.



The situation analysis consisted in collecting testimonies and information on discrimination, using the rapid research method based on individual interviews, group discussions and visits to homes of PLWHA.

The population groups concerned were:

- people living with HIV grouped into different associations;
- national and international NGOs against HIV/AIDS and those whose activities include the fight against HIV/AIDS;
- people affected by HIV/AIDS (spouses, partners, families of PLWHA);
- resource persons of associations of PLWHA;
- officials personnel of HIV/AIDS testing, care and treatment centres;
- legal institutions.

Officials of Ministries of Health, National AIDS Control Programmes (NACP) and UNAIDS representatives, partners and actors were also met.

The testimonies collected were grouped together according to the different areas of life where discrimination and stigmatization against PLWHA are more frequent.

The analysis was completed with the review of existing literature on ethical and legal problems associated with HIV/AIDS.

The entire data collected enabled to highlight the lessons learnt and propose actions aimed at putting an end to all kinds of discrimination and stigmatization, which are impeding the involvement of people infected and affected by HIV in the fight against this scourge.

In drafting the document, care was taken to respect the anonymity of the witnesses, often at their request. However, the cases narrated and reported here were based on real life experiences.

The analysis was conducted from March to July 2001 in six West and Central African countries: Burkina Faso, Cameroon, Côte d'Ivoire, Gabon, Ghana and Mauritania.

It was supervised by Dr. Pierre M'Pele, Team Leader, UNAIDS Inter-Country Team for West and Central Africa and involved the active participation of the entire Team. It was coordinated by Helene Badini, Coordinator of the GIPA Programme, with the technical collaboration of Mrs. Marie Louise N'Dala Musuamba, Magistrate and President of the Kinshasa Appeal Court, Coordinator of the National Ethics, Law and HIV/AIDS Network in the Democratic Republic of Congo and Mr. Francois Byabaramwanzi, Journalist, member and former Coordinator of Associations for the Defence of the Rights of the Individual in the Great Lakes Region (Burundi, Rwanda, Democratic Republic of Congo).

■ **Ethics**

Ethics is the science of the moral code, the art of directing human life by searching for ways of collaboration between individuals, in the mutual respect of each and everyone, mutual love, social justice and solidarity. It is based on the conscience and behaviour of each individual.

From the moment it appeared, HIV/AIDS infection posed many ethical problems, which, though specific at times, are not new, since care providers had already faced them in other pathologies.

Ethical issues have not been completely resolved, and there is no unanimity about the approach to be adopted. They are usually complex due to the media campaign around the disease, which has caused fear and anguish. Besides, the disease is depicted as a shameful pathology, since it is transmitted through sex.

■ **Rights**

It is the set of rules governing human activity. Hence, the capacity of individuals and groups to protect themselves against the infection or face it, depends on their ability to exercise their rights and assume their responsibilities.

■ **Stigmatization**

It is the fact of pointing a finger at an individual, putting a stigma on him. Stigmatization stems from several factors: denial of the disease, shame, blame, fear, rejection and discrimination.

■ **Discrimination**

Discrimination is the fact of making an unjust distinction between two elements. The result is that an individual or group of individuals suffers from unfair treatment or inequality of chances, as a result of the value judgement of other people.

■ **HIV : Human Immuno-Deficiency Virus**

HIV is the agent that causes AIDS. The virus gradually alters the immune system of the individual. It invades certain white blood cells, particularly the T4 lymphocytes and destroys them.

■ **AIDS : Acquired Immuno-Deficiency Syndrome**

- Syndrome: set of symptoms or signs;
- Immuno: the defence system of the organism;
- Deficiency: what is no longer efficient because inadequate;
- Acquired: non-hereditary.

AIDS is the consequence of an attack of the immune system during HIV infection. It is the most serious stage of the disease.

As soon as the Acquired Immuno-Deficiency Syndrome (AIDS) was discovered in Africa in the 1970s-1980s, it was perceived as a disease that defied science and wrongly associated with immoral behaviour. Scientists first of all looked for the agent responsible and focussed on the biological mechanisms of the action of the virus, the natural history of the disease and the epidemic, the means of prevention, care and treatment.

Given the urgency of the situation, issues of social ethics and rights of the infected individual were not given immediate attention.

People Living with HIV/AIDS (PLWHA) were and are still suffering from great ordeals of rejection, ostracism, moral judgements, in addition to the daily traumatizing burden of their physical and psychological experience. This situation has intensified their feeling of isolation and pushed them into despair.

Discrimination against PLWHA in the areas of employment, education, individual liberties, access to medical care, social security, access to bank loan, insurance, etc. is observed in various settings.

The respect of the rights of the HIV-infected person is one of the fundamental rights of every individual, which nearly all the African countries have enshrined in their Constitution.

Violations of these rights constitute a new challenge thrown to humanity by the HIV epidemic.

An efficient response aimed at curbing the spread of the epidemic and reducing its effects and serious socio-economic consequences should address the ethical and legal problems associated with the epidemic. The solution entails the involvement of those affected and infected, families and the communities.

It was the concern to find responses to all these issues that this situation analysis was initiated. The report defines the notions of stigmatization and discrimination, presents the cases and the lessons learnt and finally proposes actions for enhancing the respect of the rights of PLWHA.

Daily situations of discrimination and stigmatization against PLWHA highlighted in the analysis include the following:

- Employers who demand HIV testing before recruitment or communication of the results of HIV diagnosis or test;
- Treatment of PLWHA in the health centres does not fully guarantee their rights;
- In their everyday life, PLWHA are often indexed and, in some countries, they go into hiding and avoid revealing their status and getting involved in AIDS control activities.

It is to address this situation, which is the tip of the iceberg, that UNAIDS has retained as the theme of the 2002-2003 International AIDS Campaign, the fight against stigmatization and discrimination.

May this campaign open wide our ears and eyes so that responses to the epidemic could be focused on the people infected and affected in order to reduce the transmission of HIV/AIDS and its impact on Africa's already weak societies and economies.

■ Violations of the right to employment

Cases reported

O.J. versus M.O. (Ouagadougou- Burkina Faso)

Mr. O.J. was a staff of M.O. a company in Burkina.

He fell sick in 1999 and his health status necessitated his evacuation to a specialized centre in Abidjan (Côte d'Ivoire).

Instead of paying for his medical expenses, the company preferred granting him a loan to cover the amount involved, although the employees are covered by health insurance. Upon his return to Ouagadougou, the Manager of M.O. requested for the results of the test from the doctor in Abidjan, who transmitted them to him.

When the Manager learnt that O.J. was HIV-positive, he started harassing him; he was tossed from one Department to the other, without being given any responsibility. The loan for his treatment was deducted from his salary. He was refused the educational loan of CFA F 150 000 he was entitled to. When he fell sick again, the company cut his salary by 50%, the reason being that he did not regularly report for work.

He finally received a suspension letter. Instead of handing over the letter directly to the person concerned, it was delivered to his wife in the office. Yet, O.J. had not exceeded the one-year's absence recommended by the Inter-professional Collective Agreement of 9 July 1974 (Article 25). O.J. did not dare reveal his case in order not to discredit his family (O.J. was from a royal family). He rather confided in the ASS Association, which widely publicised his case. The association is currently looking for the best strategy for bringing the case before the courts.

(ASA - Burkina Faso)

Z.M., a domestic servant

Ms. Z.M. was a domestic servant working for an expatriate couple in Ouagadougou.

Her colleague (the cook) and herself were compelled to take an HIV test in the clinic run by a friend of the couple. The results were negative for the boy but positive for Ms. Z.M. The latter, doubting the results, took two other tests in different centres : the results were negative in both cases. In spite of that, her employers stuck to the test at their friend's clinic and banned Ms. Z.M. from touching their children, cutlery, dresses, etc. She was asked to perform specific tasks outside the house.

She contacted the Association "La Bergerie", which helped her to report the matter to the Labour Office. Reconciliation was impossible.

The case is now pending at the High Court, but the forces are unbalanced : the couple is assisted by Lawyers of their choice, while Ms. Z.M. is assisted by a benevolent Lawyer.

(La Bergerie - Burkina Faso)

X., a Teacher

In 1999, Mrs. X. was working as a teacher in a day nursery.

Suspecting that she was HIV-positive, the Headmistress of the school asked her to take an HIV test. The Headmistress managed to get the results before the person concerned and dismissed her.

(Ruban Rouge - Côte d'Ivoire)

At I.C.F. Company

In 1999, the I.C.F. was paralysed by a strike action by the employees, who were demanding better working conditions. The Manager asked the company doctor for a statistics on the health status of the employees. The latter complied. The number of HIV-positive employees was high. The Director exploited this information in the negotiations and used it to blackmail the employees. Under pressure from the latter, the company sacked him.

(Ruban Rouge - Côte d'Ivoire)

M.D., a Farmer

M.D., a 38-year old farmer, was working in Manso-Akropong (Ghana). When he voluntarily announced his sero-status on television, his employer dismissed him. He was recuperated by CEDEP and entrusted with lucrative activities ; he is also involved in the campaign against AIDS.

(CEDEP - Ghana)

K.Y., dismissed for being HIV-positive

Mr. K.Y., aged 36, is a widower and father of two children. After losing his job, because of his sero-status, he found a second job. But, he was fired again because the first employer revealed his sero-status to the new employer. The same employer wrote to several other employers. Mr. K.Y. was compelled to leave his country for Guinea in search of a new job.

(WISDOM - Ghana)

Fear of stigmatization

Stigmatization is so high and self-marginalization so powerful that even in structures and projects that propose free tritherapy treatment, very few PLWHA accept it. This is because they do not want to reveal their HIV-positive status. The PARVIR project of Médecins Sans Frontières (Swiss branch) proposed to offer 150 free tritherapy treatments for five years for a contribution of only CFA 50 000. However, at the end of one year, they did not even receive 30 patients. The ALLUCAM, DARVAR, PARVIX projects are facing the same difficulties.

(Recap+ - Cameroon)

Positive reaction from an enterprise

Since Mrs. M.M., a Senior Official in Cameroon, publicly announced her HIV-positive status, she received support from her superiors, her colleagues and other PLWHA in the enterprise, who even joined the "SUNAIDS" association she created. She is leading a major AIDS campaign in the enterprise under the theme "Together, let us break the killing silence of HIV/AIDS".

The enterprise has agreed to pay for her antiretroviral drugs and is doing the same for all workers who make the request. The enterprise is so much involved in the fight against AIDS that it funded the participation of the company doctor, the social worker and two nurses in the 13th International AIDS Conference, held in Durban in July 2000.

(M.M. - Cameroon)

Positive reaction from a school

Since the age of 13, Mr. K. has been teaching in a school in Mali. He teaches French in 4 classes, at the rate of 6 hours per class per week, making a total of 24 hours per week, in the mornings and afternoons. In 1997, when he announced his HIV-positive status to the head of the establishment, the latter, in agreement with the other colleagues and the district chief:

- reduced his working hours to 20 hours per week;
 - allowed him to hold most of his classes in the morning.
- Now, Mr. K. has an assistant who handles his classes while he carries out activities of his association (sensitization, external missions ...). His action has resulted in the creation, by his former pupils, of AIDS control associations in the districts (4 presently).

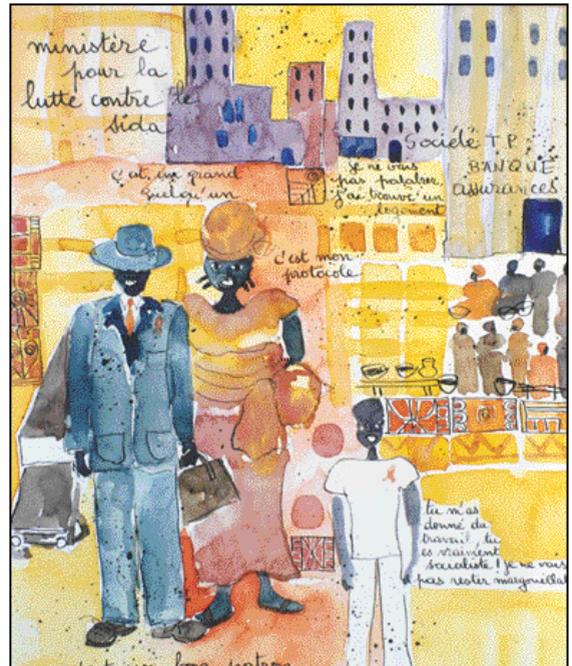
(Mali's representative at the validation workshop)

Lessons learnt

In some enterprises, as soon as an employee is declared, or even suspected of being HIV positive, the employer, worried about having to cope with a staff who, according to him, is not profitable, does everything possible to force him to resign or simply dismisses him.

Yet, the Constitution and national laws of all African countries acknowledge the right to employment without discrimination. Every individual has the right to employment, without any other condition than the requisite professional skills.

The employer should treat the employee in the respect of his dignity without any form of discrimination.



In all the countries, the general status of State employees, the Labour Code and different Collective Agreements contain provisions that protect workers.

Actions proposed

- Urging governments to adopt a legislation formally banning systematic HIV testing for purposes of employment, promotion or offer of services;
- Initiating national laws to sanction cases of violation of the right to employment;
- Encouraging public or private enterprises to develop and implement sector plans on HIV infection;
- Strengthening associations of PLWHA to make them more autonomous and active;
- Putting in place a quick and free legal procedure for resolving conflicts between employers and their employees suffering from HIV/AIDS;
- Appointing representatives of employers and trade unions to serve on national AIDS Control Committees;
- Creating Ethics Committees, including associations of PLWHA and NGOs, in places where they do not exist, or reviving those existing already;
- Putting in place "Ethics, Law and HIV/AIDS" networks, where they do not exist, and strengthening those existing already;
- Promoting the application of the "ILO Code of Practice on HIV/AIDS and the world of work".

■ Violations of the right to medical care and medical secrecy

Cases reported

In a hospital in Ghana

In one hospital in Ghana, a ward was reserved exclusively for PLWHA. The patients were not well treated. It was from a distance that some of the nurses gave them their drugs. Even those serving them food made sure they kept their distance. Doctors rarely visited them. Paradoxically, whenever donations arrived, the nurses approached the PLWHA to distribute them. Since WISDOM embarked on AIDS sensitization activities in the hospital, there has been some improvement in the behaviour of the medical staff.

(WISDOM - Ghana)

In a hospital in Ouagadougou

In some units of this hospital, patients on admission were grouped according to the nature of the disease : chronic and acute, which facilitated identification of PLWHA, given the physical deterioration and common symptoms of patients in the same ward.

(La Bergerie - a companion of PLWHA)

In treating patients on admission in the same ward, the nurses wore gloves for some of them and used their bare hands to treat others, thus facilitating the interpretation.

(La Bergerie - an AIDS patient)

In a hospital in Yaounde

Mr. Y., a worker in a hospital in Yaounde, revealed the HIV-positive status of a member of AFSU to his neighbours.

The latter attacked the lady. AFSU was not insensitive to this situation and informed officials of the hospital and members of REDS. A case was opened and investigations made. However, following threats from the Director, AFSU could not pursue the matter, especially since it was aware of the health status of the victim. She did not want to have an open confrontation with the structure, which could eventually ban members of the association from holding their pre and post-test counselling sessions there, and also avoid the matter being made public.

(AFSU - Cameroon)

In a maternity hospital

In March 2000, an HIV-positive lady with visible signs of the disease went to a maternity hospital in Abidjan to deliver.

None of the midwives wanted to go near her. She was left in the hands of interns. Only a doctor of the RED Ribbon association accepted to assist her until she delivered her baby.

(Ruban Rouge - Côte d'Ivoire)

In a health centre in Abidjan

HIV patients visiting this centre waited for a long time before they were attended to. The nurses refused to take their blood sample, and it was members of PLWHA organizations, often unqualified, who did it.

In the same centre, an associative agent posted there to cater for PLWHA was boycotted by her colleagues. The social worker categorically refused to share the same office with her.

(Lumière Action - Côte d'Ivoire)

"Where is the AIDS sufferer ?"

Members of REDS condemned the attitude of one of the officials of the hospital who told a PLWHA that she was going to die, as there was no cure for AIDS. They also reported that at the general hospital, a doctor, addressing a PLWHA in public asked : "Where is the AIDS sufferer ?".

(REDS - Cameroon)

Abandoned corpse

A member of AGASS died in a hospital. The body was abandoned on the floor until it was collected and sent to the mortuary by other members of AGASS. When interrogated, the nurses responded with a question : "Don't you know what she died of ?".

(A member of AGASS - Gabon)

Shortage of drugs

Pastor G.O. deplored the lack of drugs in health facilities. This explains why some PLWHA refuse to disclose their HIV status to their family, so as not to frighten them, given the financial expenses involved.

(Behanie Evangelization Center - Gabon)

At the Nouakchott hospital

A patient was transferred from his village to the health care centre in Nouakchott. At the unit where he was admitted, a nurse declared publicly to her ward colleagues that he had AIDS. All of them changed wards.

(SOS Peer Educators NGO - Mauritania)

Lessons learnt

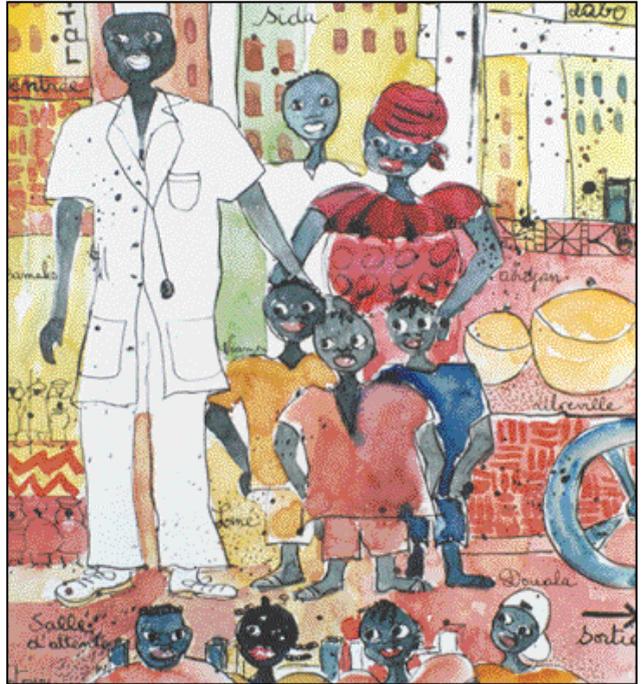
The right to health is part of the social rights that States are supposed to promote and protect. It implies the right to receive care and to have access to adequate health services.

In this regard, the right to have access to the hospital required by the state of the patient should be applied without discrimination.

However, the reality is that there are cases of underhand or open discrimination and stigmatization against PLWHA, who are powerless in the face of the authorities and solidarity of care providers.

Health care personnel have the professional and legal obligation to provide care to AIDS patients, irrespective of their state. Any breach of this obligation should be sanctioned at both the administrative and penal levels.

Concerning violation of professional secrecy, some care providers take pleasure in revealing information from medical records of PLWHA.



Some doctors working in enterprises also accept, at the request of employers, to show the medical records of patients. This generally results in the dismissal of PLWHA.

With regard to HIV testing, it was observed that in hospitals, whatever the nature of the disease, doctors systematically subjected patients to HIV testing. The results were either not communicated to the person concerned or they were announced without pre or post-test counselling, or transmitted in an envelope. In the best of cases, the candidates were sent to Ambulatory Treatment Centres (ATCs). In some cases, the first test was not followed by confirmation tests, due to lack of money, lack of information or simply because they did not exist.

Although they render great service, ATCs were sometimes reserved to PLWHA alone, thus generating fear of visiting them and, thereby aggravating stigmatization.

Actions proposed

- Strictly applying the principle of medical secrecy, and its exceptions;
- Ensuring the effective application of laws on medical confidentiality;
- Involving PLWHA in counselling at the hospital in order to better protect medical secrecy;
- Ensuring permanent training of health staff on medical code of ethics as well as ethical and clinical aspects of HIV/AIDS infection;
- Promoting family counselling for care and treatment of children.

■ Research on HIV/AIDS

Cases reported

Traditional healers in Ghana

Members of WISDOM Association in Ghana have been complaining about some traditional healers who administer unproven drugs. In fact, a member of this association died after taking products administered to him by a Togolese traditional healer who claimed to cure AIDS. Besides, WISDOM Association proposes that traditional healers should be encouraged in their research, as some indigenous drugs offer relief to AIDS patients and are also affordable.

(WISDOM - Ghana)

In a health center

Since 1991, therapeutic tests on HIV/AIDS are conducted in this centre with plants, apparently with the consent of the Burkinabe authorities.

These tests initially aroused much enthusiasm, as the products were far cheaper than ARVs.

However, users and observers alike soon became worried because the tests did not comply with the norms generally accepted in such tests:

- Those concerned did not seem to be adequately informed about the tests or the drugs administered to them; hence the condition of their informed consent was not respected.
- The treatment was not free-of-charge: those interested paid part of the cost of the tests and drugs.
- On several occasions, the prescriptions were changed in the course of treatment.
- The tests were not compared with other products already in existence or placebos
- The different stages of tests, generally respected (in vitro, on animals and then on human beings) were not followed. The tests were directly performed on humans, who were used as guinea pigs.
- Products used were not the fruit of research by the Centre. They were collected elsewhere and massively tried on PLWHA.
- Only three researchers monitored nearly 800 patients.

Shocked by such tests, the Burkinabe organizations of PLWHA condemned them in articles published in specialized reviews. Legal arguments were being gathered to institute possible legal action.

(CICDOC - Burkina Faso)

Used as guinea pigs

Members of REDS Cameroon reported that therapeutic tests were conducted on PLWHA in violation of all ethical and legal regulations enshrined in the Helsinki Declaration: lack of free and informed consent of patients, lack of scientific protocol, and especially direct tests on human beings, without prior testing on animals.

They mentioned the case of a professor who took the blood sample of a PLWHA, treated it and re-injected it into the patient.

Another case was the doctor who administered F84 to PLWHA, thinking that this product cured AIDS.

(REDS - Cameroon)

Direct therapeutic tests on PLWHA

In 1987, Mr. I.T. donated blood to a health centre in Yaounde. A week later, he was summoned by the doctor of the blood bank, who warned him against having unprotected sex. Two days later, the same doctor had him admitted, although I.T. was apparently not sick. A few hours later, another doctor visited him and promised to help him. The following morning, they took a haematoma from him, which was re-injected into him in the evening. The doctor repeated it twice a week, injecting him with another unknown product. When, in 1993, Mr. I.T. learnt that he was HIV-positive, he went to the same doctor for an explanation; the latter told him not to worry as he was already treating him. However, Mr. I.T. noted that the doctor used the same approach on several other people living with HIV, who died later. The doctor still claims to cure AIDS.

(AFSU - Cameroon)

Lessons learnt

In the area covered in the study, there is no specific regulation governing research on HIV/AIDS.

However, the same principles generally applicable to research should be applied to HIV research : informed consent, confidentiality, non-discriminatory selection of participants, equitable access to information and benefits of the research.

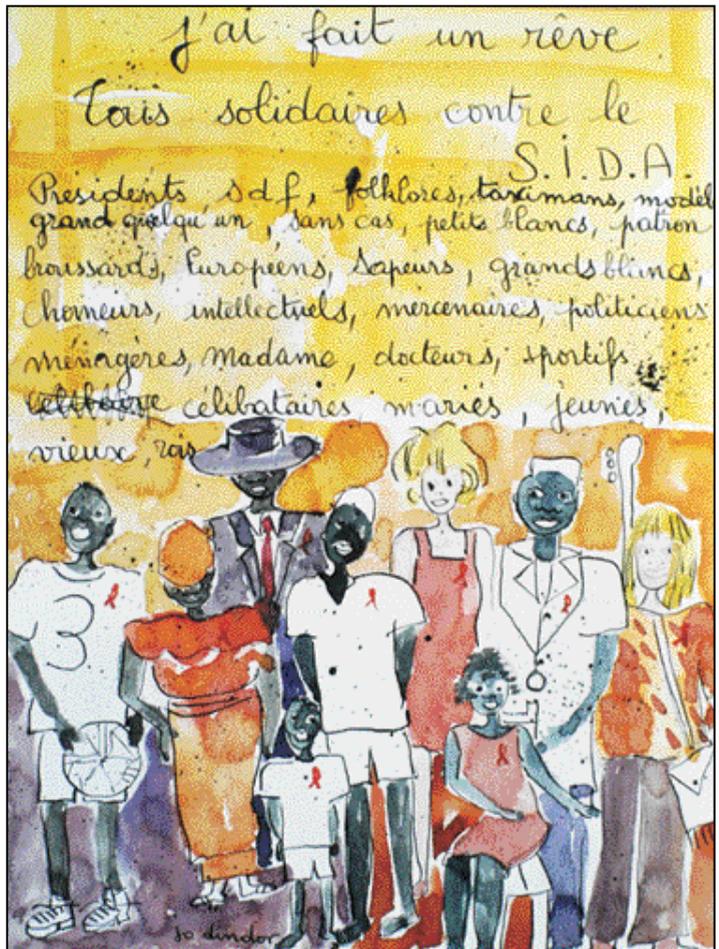
Besides, medical organizations have already looked into the problem and defined specific norms aimed at avoiding abuses.

In this regard, the 18th World Medical Assembly adopted in June 1964 in Helsinki (Finland) the Helsinki Declaration, which was amended in October 1975, October 1983, September 1989, October 1996, and recently in October 2000, by the 52nd Edinburgh Assembly (See annexes).

This Declaration should be adequately enforced in order to avoid abuses.

Actions proposed

- Ensuring the respect of international laws and conventions on research;
- Initiating repressive national laws for enforcing the Helsinki Declaration on therapeutic tests, adopted by the 18th World Medical Assembly in June 1964, as amended of date;
- Taking legal action against those who endanger the life of others by putting doubtful drugs on the market;
- Encouraging traditional healers in their research through adequate supervision;
- Sensitizing researchers and traditional healers on HIV/AIDS infection.



■ Within the family

Cases reported

F.D., a widow

Mrs. F.D., a 34-year old widow with 3 children, was chased away by her entire family (father, mother, uncles, aunts, brothers and sisters) as soon as she tested HIV-positive, following the death of her husband. Her 3 children were recuperated by her husband's family. As for her, she had no fixed home.

(WISDOM - Ghana)

Accused of killing her husband

When Mrs. T.O. lost her husband, with whom she had little children, including a baby; her in-laws immediately accused her of having "killed" their son.

The couple was living in a house built on a developed plot, and had another undeveloped plot. When she announced her HIV-positive status to her in-laws, the latter took everything from her, including the children, except the baby, who was infected.

The matter was referred to a lawyer by an association of PLWHA.

Today, she is striving to survive with her baby in another district.

(ASA - Burkina Faso)

Pension documents confiscated by in-laws

Mrs. Z.H., HIV-positive, lost her husband in 2000 and her in-laws immediately accused her of having "killed" him. The family buried him in the house where his wife lived in order to forestall any attempt to sell the property.

The family of the deceased recuperated all his pension documents. They also took away the last-born (aged 2 and a half), leaving the other children with her. But, as soon as the child started falling sick, they took him back to the mother.

The pension documents are today disputed at the Caisse Autonome de Retraite des Fonctionnaires.

(ALAVI - Burkina Faso)

She dares not claim her rights for fear of being "marabouted"

Mrs. S.M. is a member of the Association of Women Living with HIV. When her husband died, her in-laws took everything from her, but promised to look after the children. The promise was only kept for a while, because the children are today in her care. Mrs. S.M. did not dare protest for fear of being "marabouted" or killed "through witchcraft".

(AMEPOUH - Côte d'Ivoire)

HIV-positive husband wants a second child at all cost

Mr. and Mrs. X. were both HIV-positive. They had one child. Mr. X. fell sick, but after treatment with ARVs, he recuperated a bit and wanted to have a second child. His wife refused. He insisted, but to no avail. He married an uninformed young girl who quickly became pregnant.

The legitimate wife was so much affected that she had to be cared for by an association of PLWHA.

(ALAVI - Burkina Faso)

Threatened to be buried with her husband

In a village in Côte d'Ivoire, an HIV-positive farmer lost her husband who was also HIV-positive. The family and neighbours unanimously accused the woman of having killed him. On the day of the burial, the villagers demonstrated, demanding that the woman be buried with her husband. She had to seek refuge with her children in the house of an official of an association. But the latter could not cater for them for too long, for lack of resources.

The woman returned to her village. She is without resources or treatment.

(Virus Village Association - Côte d'Ivoire)

Threatened with death

Mrs. S.S., aged 30 and mother of two, was contaminated by her HIV-positive concubine. In 1998, she decided to get involved in the fight against AIDS, within associations and to testify on television. In 1999, her concubine committed suicide and since then she has been receiving death threats from her in-laws, who accused her of killing their son.

After taking away all her property, the in-laws threatened to kill her.

(AGAAS - Gabon)

Rights and Pension

Mrs. N.A., aged 28, a member of an association of PLWHA, became completely helpless when her husband died of AIDS.

Her in-laws did not want to give her anything, for the simple reason that they were not legally married. But, the young woman believed that since she was dowered and had been contaminated by this man, she had the right, for her treatment, to a major share of the amount of F CFA 8 000 000 that the enterprise paid as final settlement. The lawyer is holding on to the cheque until the two families reach a compromise arrangement.

(AGAAS - Gabon)

"Go with your house!"

Mrs. I.K.D., aged 28, a member of an association of PLWHA reported that she built a house on her aunt's plot, where she used to live with her son. When she was declared HIV-positive, and she started giving testimonies, her aunt chassed her from the compound, asking her to go with her house.

(AGAAS - Gabon)

X. kept the secret of his HIV-status until his death

The NGO STOP SIDA followed for 6 months the case of a married, monogamous HIV-positive man, who was a highly esteemed technician, but often fell sick.

Suffering from acute diarrhoea, he refused to go for treatment and his wife attributed the cause of his disease to witchcraft.

On the insistence of UNAIDS/Mauritania, he finally agreed to go to the hospital where he died shortly afterwards, without ever informing his wife that he was HIV-positive.

He left behind two orphans, aged 3 and 2. The mother, who was herself HIV-positive, accepted that the younger of the children be tested in order to keep some hope according to her. Today, this woman has agreed to testify, but categorically refused to be filmed or named, for fear of stigmatization.

(NGO STOP AIDS - Mauritania)

Considered as a shame on the family

A member of an NGO has, in his family, a cousin who recently returned from a neighbouring country. Sick, lean, hardly recognizable, he was considered as a shame on the family. His wife hid him in a house that was always closed (contrary to usual habits). It took even his own sisters one month before they learnt that he was back.

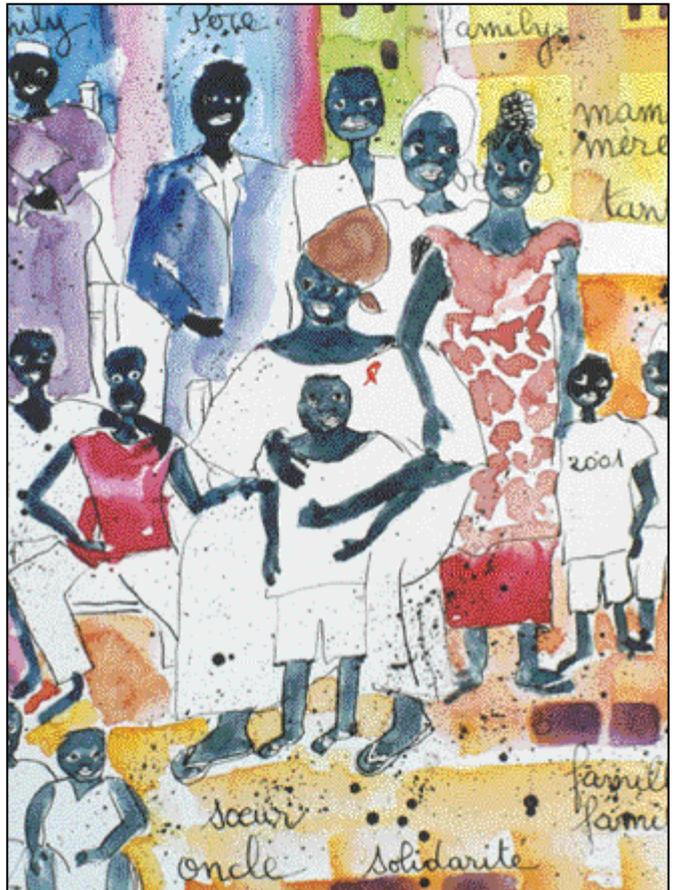
(SOS Peer Educators)

Lessons learnt

Generally, as soon as the family learns that one of its members is HIV-positive, the tendency is to isolate him or even chase him away. The family feels dishonoured and fears contamination. Cases of suicide of parents following the announcement of the HIV status of their child have already been reported.

In such a hostile environment, some PLWHA, even those who militate within associations, dare not announce their HIV status to their family. They live in hiding, under heavy moral constraint, and in anguish.

The family's ignorance of their disease seriously hampers sensitivity to HIV/AIDS and constitutes a major setback in the fight against the epidemic.



Moreover, within the family, it is women who are particularly stigmatized.

The inferior status of the woman pursues her in case of HIV infection. Within the couple, she has no right to express herself, because of her economic dependency, and our customs and traditions.

Women should overcome many obstacles in order to avoid risks of HIV infection.

Men often refuse to be tested for HIV/AIDS and to use the condom. They prefer chasing away the wife and marrying another woman.

Actions proposed

- Sensitizing the family and the community on the rights and duties of PLWHA;
- Sensitizing the family and the community on the duties of widows and orphans;
- Promoting voluntary testing;
- Encouraging couples to engage in more dialogue on sexuality and HIV/AIDS issues;
- Promoting HIV testing of couples;
- Encouraging the population to make their wills so that children are not deprived of the property of their parents on the death of the latter;
- Supporting associations of PLWHA in their actions in order to ensure greater efficiency.

■ Rejection by close relatives and friends

Cases reported

Intolerance

Mr. B.Y., aged 34, was married with 3 children, one of whom recently died of AIDS. He was declared HIV-positive in 1995, when he was a civil servant in charge of sports for students and teachers. His HIV sero-status affected him and he told himself that his death was imminent. It was after meeting with an "Ambassador of hope" that he realized that his life was not lost and that he could still hope to live longer and continue to be useful to the society. Since then, he got involved in the fight against HIV/AIDS. After featuring on radio and television programmes, he became a victim of stigmatization. He decided to stop working and devote himself to the fight against AIDS. His landlord ejected him, for the reason that he could not "accommodate an HIV-infected person".

(WISDOM - Ghana)

As in a zoo

In a research centre in Abidjan, the interns come to look at AIDS patients like animals in a zoo. The same unhealthy curiosity was observed when people came, sometimes from far away, to "see the AIDS sufferers".

(A doctor's testimony - Côte d'Ivoire)

Even in well-to-do circles

Mr. J.S., coordinator of an Ivorian Association against AIDS, fell sick. His brother was "somebody", as they say in Côte d'Ivoire, an executive in a company. When Mr. J.S. disclosed his HIV-positive status to his brother, the latter chased him from his villa in the posh Riviera district, because he did not want to have an AIDS patient in his family. When he was admitted at the hospital, he was assisted by colleagues of the association. When his condition improved, his brother sent him to the village with a tape recorder to listen to music. But, when he died, his brother refused that friends of the association took care of his body. He organized a grand funeral for him in their village.

(Club des Amis - Côte d'Ivoire)

Only the father shows understanding

Ms. A.E. was living with her paternal family in Côte d'Ivoire. When she learnt of her HIV-positive status, she informed her close family members. Her brother, although a health worker, immediately rejected her: refusal to share the cutlery, bathroom. She was also banned from touching the children. Only her mother's family, composed of illiterates, showed understanding. Her father finally became indulgent, and used his authority to get the other family members to accept her. Today, their behaviour has changed and the family is lavishing attention upon Ms. A.E.

(Club des Amis - Côte d'Ivoire)

Salesgirl in a drugstore

Mrs. M.M., HIV-positive, was a salesgirl in a drugstore in Abidjan. She often fell sick and absented herself from work. One day, one of her colleagues showed her treatment card to the Manageress. Since then, all the colleagues refused to work with her, and started spreading the news of her HIV status. Discouraged, Mrs. M.M. herself requested to leave the drugstore, but without being accompanied. As she did not have any resources, she resorted to benevolent associations for ARVs.

(NAP+ - Côte d'Ivoire)

Even in families of doctors

Mrs. B.C. has a half-sister doctor working in an AIDS control project. The latter contributed to the poor treatment that B.C. suffers from her own family, until she finally left to join her mother who had remarried and who did not have the means to cater for her. She finally had to rely on her church, and later returned to her village to die there.

(GAP+ PS - Côte d'Ivoire)

Scolded by the neighbours

The mother of Ms. X., a member of AFSU, was scolded in the district because her neighbour saw her daughter visiting another AFSU member. The girl had to use all her diplomacy to explain to the mother that she was not infected with HIV/AIDS, that she only went to see a friend, and that not all AFSU members were infected with HIV/AIDS.

(A member of AFSU - Cameroon)

The parents commit suicide

Both parents of Ms. K.J. committed suicide as soon as they learnt that their daughter was HIV-positive. The latter went to live at her aunt's house, where she had her own cutlery and anything she used was not be touched by the other members of the family. She could not even touch her own daughter.

(Members of AFSU - Yaounde - Cameroon)

A mother's suicide

A Cameroonian woman decided to commit suicide as soon as she discovered her daughter's sero-status. She stayed day and night without drinking, eating or sleeping. For 6 days, she sat at the same place in the courtyard and finally died.

(AFSU - Cameroon)

Dismissed from school

Little M.H., aged 10 and HIV-positive, was attending primary school in Abidjan. He was infected through blood transfusion after a car accident.

M.H. was quite fragile and often fell sick; his classmates and teacher were aware that he suffered from HIV/AIDS. One day, the Headmistress of the school summoned his parents and told them that she did not want to see M.H. in her establishment, on the pretext that he could contaminate the other children, and that her school was not a medical centre. The following morning, he wanted to go to school as usual but his parents dissuaded him. M.H. died one year later. His parents took legal action against the Headmistress of the establishment, but to no avail.

(Lumière Action - Côte d'Ivoire)

Fear of being recognized

When visiting homes to provide care to PLWHA, the vehicle of ATC Gabon could not stop in front of the houses. It had to park more than a kilometre away in order not to attract the attention of the neighbours. Everything had to be done to ensure that the patients were not identified.

(Members of ATC - Gabon)

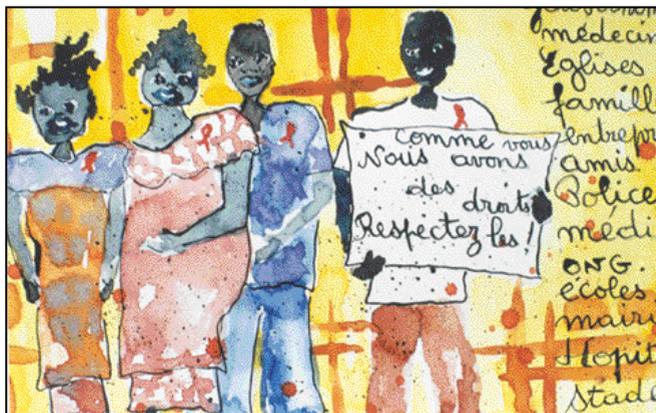
X., indexed by close relatives

Mr. X. was HIV-positive and working abroad. After graduation, he returned to Nouakchott where he started developing the disease. Rumour went round that he was suffering from HIV/AIDS. Stigmatized by members of his family and close relatives, he had to run away. It was on the intervention of the NGO STOP SIDA, which took a lot of time to explain that AIDS was a disease like any other disease, that the family finally understood and Mr. X. was able to return to his home.

(NGO STOP AIDS - Mauritania)

Lessons learnt

HIV/AIDS is considered as a taboo disease, a disease of shame. Close relations of those suffering from the disease are generally hostile. The PLWHA is mocked at and indexed. He is in a position of weakness, abandonment and extreme isolation before a community he cannot confront.



When a person is publicly declared HIV-positive, the initial hostility he has to face is that of his immediate relatives : father, mother, brothers and sisters, spouse, friends, neighbours, colleagues, etc.

A priori, a feeling of solidarity should be imposed on all close relatives after the announcement of such a serious misfortune. But, this is not the case. Nobody wants to share "shame".

Besides, ignorance of the modes of AIDS transmission often compels individuals, or even families to reject their relatives suffering from HIV/AIDS. The population ignores everything about care and treatment and what can be done to assist them. It therefore becomes practically legitimate to adopt an attitude of mistrust and reservation towards the unknown.

Actions proposed

- Organizing vast sensitization and information campaigns, with the emphasis on the fundamental rights of PLWHA;
- Developing and disseminating messages on prevention, care and treatment in order to encourage positive behaviour change;
- Establishing networks on ethics, law and HIV/AIDS in each African country or revitalizing those already existing so that they can contribute to the creation of a conducive environment for the emergence of positive and efficient community responses to HIV/AIDS infection;
- Equipping the networks with toll-free telephone lines for reporting all cases of discrimination;

- Formally banning in each Constitution discrimination based on sero-status;
- Creating legal assistance centres within each network;
- Strengthening associations of PLWHA and providing them with adequate means to undertake actions at all levels of the population;
- Providing greater support to leaders of associations of PLWHA to enable them to conquer fear, accept their situation and be accepted by others;
- Combating self-stigmatization and isolation;
- Developing campaigns on solidarity and tolerance towards PLWHA;
- Developing networks of journalists and training them to fight against AIDS;
- Encouraging the creation of associations of PLWHA in Mauritania;
- Going to meet Mauritanian PLWHA to help get them out of their ghetto;
- Conducting systematic and in-depth surveys to determine the exact number of HIV-positive people in Mauritania.

■ Stigmatization in religious circles

Cases reported

X., excluded from her Church

A member of an HIV/AIDS association was very active in her parish. She was excluded on the pretext that "she was living in sin".

In the same Church, the pastor requested an HIV-positive woman to publicly confess her sins before the congregation.

(Ruban Rouge - Côte d'Ivoire)

Obliged to change priest for her marriage

Mrs. X., a member of an HIV/AIDS association in Abidjan wanted to get married. To prepare the marriage, she contacted a priest of her parish, who willingly agreed to guide her, but as soon as he learnt that she worked for an association that supports PLWHA, the priest became distrustful and started avoiding her.

She had to find another priest and everything was sorted out.

(Ruban Rouge - Côte d'Ivoire)

D.E., HIV-positive, should be the last to receive communion

Mr. D.E., a teacher in Côte d'Ivoire, is a member of a Church of the Assemblies of God. Following an indiscretion of a "brother" he met in the house of a traditional healer, his fellow church members learnt about his HIV-positive status. Since then, at the communion (with bread and wine) they by-pass him and ensure that he is the last to receive communion.

(Lumière Action - Côte d'Ivoire)

"PLWHA will be punished up to the 5th generation"

Members of REDS/Yaounde also noted the condemnation of PLWHA by some priests. The latter do not hesitate to invite PLWHA in the middle of the service for special prayers, because they "have sinned and would be punished up to the 5th generation".

(REDS - Cameroon)

Abandoned

In a prayer group, a woman felt she was targeted by the pastor who shouted that the HIV-positive woman in the group should show herself. She did so and since then, she has been having a lot of problems with her family and in her area where she is stigmatized. The pastor does not know how he can assist her.

(Members of ATC - Gabon)

"AIDS is a punishment from GOD"

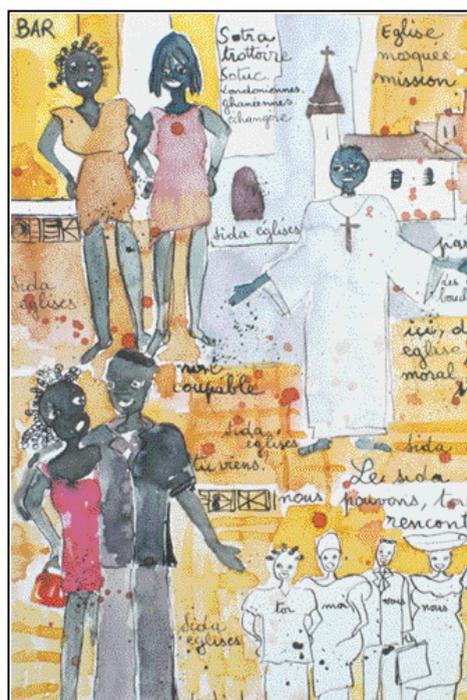
In one church in Gabon, a pastor, in his preaching, blamed PLWHA in the following terms: "AIDS is a punishment from God. When those infected with HIV become bedridden, they accuse their parents of being the cause of their disease. Be careful, many of you come to church in search of comfort...". The PLWHA present at the church service were exceedingly shocked and one of them took the floor to express his indignation and talk about their spiritual need. Since then, the pastor has changed his language.

(AGASS - Gabon)

Lessons learnt

In some Churches, prayer groups and sects, the pastors condemn PLWHA. HIV/AIDS is considered as a disease of sin, sexual vagrancy, a punishment from God. The solution for PLWHA, who are sometimes treated as witches, is to withdraw and stop participating in these assemblies, whereas they need moral and spiritual support.

There are religious leaders who perfectly understand the AIDS pandemic, its modes of transmission and means of control. Some of them try to treat the disease with prayers, holy water or imposition of hands. Others, on the contrary, affirm that AIDS is a sign of degeneracy of the society, that the Bible predicted the coming of the scourge, that it should be controlled by recommending fidelity and combating adultery.



Diagnosis of HIV infection has considerable psychological effects (state of shock, denial, anger, suicidal tendencies, fear, depression, isolation, guilt, anguish, etc).

The fear of death may arouse an interest for spiritual matters among PLWHA. The moral authorities of Churches and prayer groups should not take advantage of this situation to propagate lies (healing powers...) with heavy ethical and legal consequences, but rather help with the accompaniment and spiritual support of PLWHA.

Actions proposed

- Condemning fraudulent practices of sects on the pretext of curing PLWHA;
- Developing partnership between religious leaders and HIV/AIDS organizations;
- Sensitizing religious leaders on the implementation of the Libreville Declaration;
- Training religious leaders on HIV/AIDS infection.

■ Banking and insurance

Cases reported

Doubtful features

Mr. N.A. is a senior official in a Ouagadougou establishment. When he applied for an educational loan from a local bank, the bank officials hesitated because of his physical appearance and asked him for supplementary medical examinations. He withdrew his application.

(Reported by ASA - Burkina Faso)

HIV test required

Mrs. M.M., whose enterprise had to change its insurance company in 1999, was asked to fill in a new form for the new contract. The forms contained questions on sero-status. She gave a negative response, whereas the medical consultant of the new insurer was aware of her HIV-positive status. She was invited by the medical consultant whom she asked to officially write to her enterprise that the Insurer was refusing to cover her because of her sero-status. Finally, the insurance cover was not withdrawn and she is even enjoying a better social coverage, as the enterprise is bearing the full cost of her antiretroviral drugs, instead of the 80% refund applied to other drugs by the insurance company.

(RECAP+ - Cameroon)

Lessons learnt

Prior to the signing of an insurance contract, companies generally request prospective clients to take a medical examination, which includes a blood test.

Even if the results are not sent directly to the management of the company, the medical consultant takes the results into account in determining who is "insurable" and who is not. HIV-positive applicants have no chance of featuring on the list of "insurable".

Banks operate in the same manner since they also require life insurance before granting a certain amount of credit requested.

Actions proposed

- Initiating laws banning discrimination in the area of insurance and bank loans, in accordance with ILO's Code of Conduct on HIV/AIDS and the world of work;
- Ensuring a wide dissemination of the ILO's Code of Conduct.

■ Immigration and travel

Cases reported

Refusal of Visa

Mr. K.P., after passing his Master's degree in Physical Mathematics at the University of Abidjan, took an Engineering test to enter a western university, which he also passed.

When Mr. K.P. went to the Embassy to apply for a visa, he was made to take the HIV/AIDS test. Since the test was positive, the Embassy refused to issue the visa to him. Consequently, Mr. K.P. could not pursue his studies.

(Lumière Action - Côte d'Ivoire)

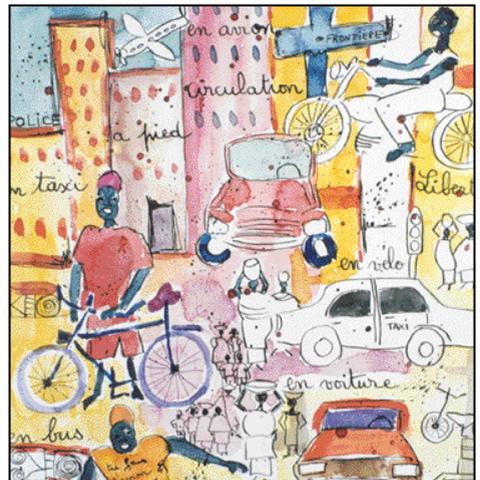
A Cameroonian lady married to an expatriate applied for a visa from a western Embassy. She was asked to take the HIV test, which was positive. She was refused the visa and her husband had to return to his country alone. The two have since separated.

(AFSU - Cameroon)

Lessons learnt

Many developed countries refuse entry to HIV-positive people, either because they represent a danger for public health or because the care and support they would need would be too expensive for the host country.

African immigrants are of course the first people concerned, as they are presumed infected. Applicants for scholarships to study in western countries were regularly exempted because the test (conducted by a doctor of the Embassy) was positive.



Yet, it is stipulated in Article 13 of the Universal Declaration of Human Rights that:
"1/ Every person has the right to move freely and choose his residence within a State.
2/ Every person has the right to leave any country including his own, and to return to his country".

Hence, asking travellers to produce an HIV-negative certificate is unjustified.

Action proposed

- Ensuring advocacy at the international level in the area of immigration policies in order to facilitate the issue of visas and award of scholarships without prior compulsory HIV/AIDS test;
- Ensuring advocacy for the adoption of legislative tests on free movement of PLWHA.

Situation analysis of discrimination and stigmatization against People Living with HIV/AIDS in West and Central Africa

Synthesis

Areas	Problems	Actions
Employment	<ul style="list-style-type: none"> • HIV test required for employment • Medical file transmitted to employer • Harassment • Non-application of the law on sick leave • Compulsory tests in the course of contract • Discrimination and stigmatization at the work place 	<ul style="list-style-type: none"> • Banning of HIV tests for purposes of employment, promotion or payment of allowances • Promulgating laws sanctioning violations of right to employment • Encouraging enterprises to take measures against discrimination and stigmatization of PLWHA by developing a policy on HIV infection at the work place • Promoting the institution of HIV control programmes in enterprises
Medical care and medical secrecy	<ul style="list-style-type: none"> • Violation of medical secrecy • Isolation of HIV patients in special wards • Neglect or rejection of patients by the medical and social staff • Refusal of health care • Systematic testing 	<ul style="list-style-type: none"> • Ensuring strict respect of medical secrecy. • Enforcing sanctions provided for by the Medical Code of Ethics and the Penal Code • Enhancing the skills of socio-health personnel
Therapeutic research	<ul style="list-style-type: none"> • Using human beings as guinea pigs • Direct tests on human beings • Refusal to inform those concerned about tests conducted • Change of treatment during tests 	<ul style="list-style-type: none"> • Ensuring compliance with the law on research and existing conventions • Initiating national repressive laws to enforce the Helsinki Convention on therapeutic tests • Taking legal action against people who put into danger the life of the population by marketing inefficient drugs • Supporting traditional medicine through appropriate supervision • Promoting frameworks for exchange and sharing of experiences at the international level
Family	<ul style="list-style-type: none"> • Expulsion of the widow • Separation of the children from their mother • Confiscation of property by the husband's family • Refusal of men to subject themselves to testing • Lack of dialogue on sexuality • Death threats against the widow • Rejection 	<ul style="list-style-type: none"> • Intensive sensitization of the populations on the rights of widows and orphans • Encouraging couples to engage in more dialogue on sexuality and AIDS problems • Sensitizing the population on the necessity of prenuptial medical examinations • Encouraging the population to make wills • Promoting couple testing

Synthesis (continuation)

Areas	Problems	Actions
Close relatives and friends	<ul style="list-style-type: none"> • Abandonment of the patient • Denigration • Discriminatory language 	<ul style="list-style-type: none"> • Widespread sensitization campaigns for better information on AIDS • Creating legal assistance centres for PLWHA • Developing prevention, care and treatment messages to encourage positive behaviour changes • Establishing networks on ethics, law and HIV/AIDS in each country or revitalizing those existing, in order to create a conducive environment for the emergence of efficient, positive, and community responses to HIV/AIDS infection • Equipping the networks with "green numbers" for reporting cases of discrimination • Formally banning in the Constitution, discrimination based on sero-status
Religion	<ul style="list-style-type: none"> • Exclusion of PLWHA • Refusal spiritual assistance • Making feel guilty • Promise of miraculous healing 	<ul style="list-style-type: none"> ■ Sensibilization on HIV/AIDS in religious circles ■ Initiating partnership with religious and associations leaders ■ Pursue into Justice those misleading the population
Backward cultural practices	<ul style="list-style-type: none"> • Levirate, sororat, polygamy 	<ul style="list-style-type: none"> ■ Promoting local response to HIV ■ Encouraging community exchanges on socio-cultural practices and habits in the context of HIV ■ Disseminating the Family Code and other texts condemning backward practices
Banking and insurance	<ul style="list-style-type: none"> • Compulsory HIV test 	<ul style="list-style-type: none"> ■ Introducing laws banning discrimination in banking and insurance
Immigration and travel	<ul style="list-style-type: none"> • Compulsory test for issue of visa • Refusal of entry to PLWHA 	<ul style="list-style-type: none"> • Advocacy at the international level for the adoption of legislation promoting the free movement of PLWHA



Conclusion

The basic factors underlying stigmatization are fear, shame, intolerance and rejection of the other.

Due to the fear of dying from a disease that is still not well known, the fear of being infected, ignorance of the modes of transmission, terrifying representations of people infected, everybody prefers to keep away from those who have started developing the disease or who disclose their HIV-positive status.

In Africa, AIDS is a shame for the family. In a study conducted on 731 people in the northern district of Botswana in 1999 (cf. forum internet - stigma/UNAIDS-23032001), several of the people surveyed proposed extreme solutions for eradicating AIDS : killing HIV carriers either by burning them or by "euthanizing" them in the hospital, by marking them on the body in the form of tattoo under the armpit, by isolating them in homes, etc.

This proves that we are still far from a real knowledge of the disease and much less of its acceptance by the community. Only a few rare countries, like Uganda, have succeeded in attaining an acceptable level of tolerance, acceptance and solidarity. The others are still at the level of fear, rejection and stigmatization.

This is therefore the time to mobilize the entire African community with a view to combating discrimination and stigmatization against PLWHA.

The experience and knowledge acquired in the area of this pandemic show that issues of law, ethics and rights of the individual are of capital importance for combating discrimination and stigmatization against PLWHA and for achieving social and behavioural change, while reducing the impact of the epidemic.

There is therefore need for a collective, concerted and sustainable action, taken within a conducive, legal and ethical environment, for protecting individual liberties and fundamental rights, as well as preserving the dignity of PLWHA.

Only such an environment can enable those infected and affected by HIV/AIDS to overcome their condition, live positively and remain responsible and productive members within their community.

Hence, they will be able to use their testimony and unique contribution, based on their experience and their new vision, to enrich the community response to HIV infection.

Each of us has a role to play.

As Mr. Peter Piot, Executive Director of UNAIDS, declared at the Abidjan ICASA (Dec. 1991): "...Break the silence surrounding AIDS ... I invite all political leaders of African countries to use their authority to open the eyes of their community. It costs nothing to talk about AIDS. If you protect them from discrimination and stigmatization, HIV-infected people will dare speak openly about their situation of despair. This will urge others to go in for voluntary testing ..."

■ Helsinki Declaration

Adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964 and amended by the:

- 29th WMA General Assembly, Tokyo, Japan, October 1975
- 35th WMA General Assembly, Venice, Italy, October 1983
- 41st WMA General Assembly, Hong Kong, September 1989
- 48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996
- 52nd WMA General Assembly, Edinburgh, Scotland, October 2000

► **Introduction**

1. The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principles to provide guidance to physicians and other participants in medical research involving human subjects. Medical research involving human subjects includes research on identifiable human material or identifiable data.
2. It is the duty of the physician to promote and safeguard the health of the people. The physician's knowledge and conscience are dedicated to the fulfillment of this duty.
3. The Declaration of Geneva of the World Medical Association binds the physician with the words, "The health of my patient will be my first consideration" and the International Code of Medical Ethics declares that "A physician shall act only in the patient's interest when providing medical care which might have the effect of weakening the physical and mental condition of the patient."
4. Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects.
5. In medical research on human subjects, considerations related to the well-being of the human subject should take precedence over the interests of science and society.
6. The primary purpose of medical research involving human subjects is to improve prophylactic, diagnostic and therapeutic procedures and the understanding of the aetiology and pathogenesis of disease. Even the best proven prophylactic, diagnostic, and therapeutic methods must continuously be challenged through research for their effectiveness, efficiency, accessibility and quality.
7. In current medical practice and in medical research, most prophylactic, diagnostic and therapeutic procedures involve risks and burdens.
8. Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. Some research populations are vulnerable and need special protection. The particular needs of the economically and medically disadvantaged must be recognized. Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those for whom the research is combined with care.
9. Research Investigators should be aware of the ethical, legal and regulatory requirements for research on human subjects in their own countries as well as applicable international requirements. No national ethical, legal or regulatory requirement should be allowed to reduce or eliminate any of the protections for human subjects set forth in this Declaration.

► **Basic principles for all medical research**

1. It is the duty of the physician in medical research to protect the life, health, privacy, and dignity of the human subject.
2. Medical research involving human subjects must conform to generally accepted scientific principles, be based on a thorough knowledge of the scientific literature, other relevant sources of information, and on adequate laboratory and, where appropriate, animal experimentation.
3. Appropriate caution must be exercised in the conduct of research which may affect the environment, and the welfare of animals used for research must be respected.
4. The design and performance of each experimental procedure involving human subjects should be clearly formulated in an experimental protocol. This protocol should be submitted for consideration, comment, guidance, and where appropriate, approval to a specially appointed ethical review committee, which must be independent of the investigator, the sponsor or any other kind of undue influence. This independent committee should be in conformity with the laws and regulations of the country in which the research experiment is performed. The committee has the right to monitor ongoing trials. The researcher has the obligation to provide monitoring information to the committee, especially any serious adverse events. The researcher should also submit to the committee, for review, information regarding funding, sponsors, institutional affiliations, other potential conflicts of interest and incentives for subjects.
5. The research protocol should always contain a statement of the ethical considerations involved and should indicate that there is compliance with the principles enunciated in this Declaration.
6. Medical research involving human subjects should be conducted only by scientifically qualified persons and under the supervision of a clinically competent medical person. The responsibility for the human subject must always rest with a medically qualified person and never rest on the subject of the research, even though the subject has given consent.
7. Every medical research project involving human subjects should be preceded by careful assessment of predictable risks and burdens in comparison with foreseeable benefits to the subject or to others. This does not preclude the participation of healthy volunteers in medical research. The design of all studies should be publicly available.
8. Physicians should abstain from engaging in research projects involving human subjects unless they are confident that the risks involved have been adequately assessed and can be satisfactorily managed. Physicians should cease any investigation if the risks are found to outweigh the potential benefits or if there is conclusive proof of positive and beneficial results.
9. Medical research involving human subjects should only be conducted if the importance of the objective outweighs the inherent risks and burdens to the subject. This is especially important when the human subjects are healthy volunteers.
10. Medical research is only justified if there is a reasonable likelihood that the populations in which the research is carried out stand to benefit from the results of the research.
11. The subjects must be volunteers and informed participants in the research project.
12. The right of research subjects to safeguard their integrity must always be respected. Every precaution should be taken to respect the privacy of the subject, the confidentiality of the patient's information and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject.

13. In any research on human beings, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail. The subject should be informed of the right to abstain from participation in the study or to withdraw consent to participate at any time without reprisal. After ensuring that the subject has understood the information, the physician should then obtain the subject's freely-given informed consent, preferably in writing. If the consent cannot be obtained in writing, the non-written consent must be formally documented and witnessed.
14. When obtaining informed consent for the research project the physician should be particularly cautious if the subject is in a dependent relationship with the physician or may consent under duress. In that case the informed consent should be obtained by a well-informed physician who is not engaged in the investigation and who is completely independent of this relationship.
15. For a research subject who is legally incompetent, physically or mentally incapable of giving consent or is a legally incompetent minor, the investigator must obtain informed consent from the legally authorized representative in accordance with applicable law. These groups should not be included in research unless the research is necessary to promote the health of the population represented and this research cannot instead be performed on legally competent persons.
16. When a subject deemed legally incompetent, such as a minor child, is able to give assent to decisions about participation in research, the investigator must obtain that assent in addition to the consent of the legally authorized representative.
17. Research on individuals from whom it is not possible to obtain consent, including proxy or advance consent, should be done only if the physical/mental condition that prevents obtaining informed consent is a necessary characteristic of the research population. The specific reasons for involving research subjects with a condition that renders them unable to give informed consent should be stated in the experimental protocol for consideration and approval of the review committee. The protocol should state that consent to remain in the research should be obtained as soon as possible from the individual or a legally authorized surrogate.
18. Both authors and publishers have ethical obligations. In publication of the results of research, the investigators are obliged to preserve the accuracy of the results. Negative as well as positive results should be published or otherwise publicly available. Sources of funding, institutional affiliations and any possible conflicts of interest should be declared in the publication. Reports of experimentation not in accordance with the principles laid down in this Declaration should not be accepted for publication.

► ***Additional principles for medical research combined with medical care***

1. The physician may combine medical research with medical care, only to the extent that the research is justified by its potential prophylactic, diagnostic or therapeutic value. When medical research is combined with medical care, additional standards apply to protect the patients who are research subjects.
2. The benefits, risks, burdens and effectiveness of a new method should be tested against those of the best current prophylactic, diagnostic, and therapeutic methods. This does not exclude the use of placebo, or no treatment, in studies where no proven prophylactic, diagnostic or therapeutic method exists.

3. At the conclusion of the study, every patient entered into the study should be assured of access to the best proven prophylactic, diagnostic and therapeutic methods identified by the study.
4. The physician should fully inform the patient which aspects of the care are related to the research. The refusal of a patient to participate in a study must never interfere with the patient-physician relationship.
5. In the treatment of a patient, where proven prophylactic, diagnostic and therapeutic methods do not exist or have been ineffective, the physician, with informed consent from the patient, must be free to use unproven or new prophylactic, diagnostic and therapeutic measures, if in the physician's judgement it offers hope of saving life, re-establishing health or alleviating suffering. Where possible, these measures should be made the object of research, designed to evaluate their safety and efficacy. In all cases, new information should be recorded and, where appropriate, published. The other relevant guidelines of this Declaration should be followed.

■ Dakar Declaration (1st July 1994)

- Acknowledging the impact of the HIV epidemic on all aspects of human life ;
- Acknowledging the need for an urgent response ;
- Acknowledging that the basic value of the respect of individual rights, respect of human life constitutes the basis of any action ;

We, participants of the Intercountry consultation of the African Network on Ethics, Law and HIV, affirm that any action, taken at individual, institutional, professional or governmental level, in response to the HIV epidemic should be guided by the following principles:

► **Principle of responsibility**

Every individual, government, community, institution, private enterprise and media should be aware of their responsibility and should exercise it in an active and continuous manner.

► **Principle of commitment**

Every person is affected, directly or indirectly and should therefore feel concerned by the epidemic and react to it by getting involved with courage and hope in the future.

► **Principle of partnership and consultation**

All individuals, couples, families, communities and nations should work together with empathy, in order to strive for the realization of a common and shared vision. Such partnerships should reflect and actively promote solidarity, inclusion, integration, dialogue, participation and harmony.

► **Principle of non-discrimination**

Any person directly or indirectly affected by the epidemic should remain an integral part of his community with the same right to work, to housing, to education, to social services, with the right to marriage, to freedom of movement, belief and association, with the right to counselling, care and treatment, justice and equity.

► **Principle of confidentiality and respect of private life**

Any person directly affected by the epidemic has the right to confidentiality and respect of his private life. This right may only be restricted under exceptional circumstances.

► **Principle of adaptation**

Every individual or community should promote change and adaptation of the socio-cultural conditions to the requirements of the epidemic in order to ensure the efficiency of the response.

► **Principle of the use of an adapted language**

The language should respect human dignity and reflect inclusion; it should be sensitive to gender issues; it should be precise and comprehensible.

► **Principle of ethics in research**

The interests of individuals and communities involved in research projects are essential. The research should be conducted on the basis of a free and informed consent without intrusion in private life and without coercion. The results of the research should be made available to the community for an appropriate and opportune action.

► **Principle of banning compulsory testing**

All HIV testing without prior informed consent should be banned. Moreover, HIV testing should not be required for access to employment, travel, or any other service.

■ Associations of PLWHA

Organization Association	City/ Country	Contact person	Tel/Fax	E-mail
Association Santé pour tous	Ouagadougou Burkina Faso	Mr. Roch Zongo (President)	(226) 37 16 38 (226) 32 41 88	
African Solidarity Association (ASA)	Ouagadougou Burkina Faso	Mr. Issouf Tiendrébéogo (President)	(226) 31 01 47 (226) 31 87 62	aas@fasonet.bf
Association La Bergerie	Ouagadougou Burkina Faso	Mr. Wendtoin ouédraogo (President)	(226)34 41 51 (226) 34 19 66	fucompassion@liptinfor.bf
Association ALAVI	Ouagadougou Burkina Faso	Mrs. Laure Salambere (President)	(226) 36 91 16	alavi95@hotmail.com
Association Vie Positive	Ouagadougou Burkina Faso	Mr. Amidou Kaboré (President)	(226) 23 67 74 (226) 30 81 91	viepositive@hotmail.com
CICDOC (Centre d'Information, de Conseil et de Documentation sur le VIH/SIDA)	Ouagadougou Burkina Faso	Dr. Pascal Nyamba	(226) 31 10 26 (226) 31 41 59	cicdoc.assoc@cenatrin.bf cicdoc.doc@cenatrin.bf
Society of Women against AIDS in Africa (SWAA)	Ouagadougou Burkina Faso	Dr. Claude Millogo (President)	(226) 31 23 94	
Society for Women against AIDS in Africa (SWAA)	Yaounde Cameroon	Mrs. Patricia Ndikum	(237) 223 05 876	
Association des Frères et Sœurs Unis (AFSU)	Yaounde Cameroon	Mr. Issac Tita (President)	(237) 222 62 58	presica@uycdc.uninet.cm afsucameroun@yahoo.fr
Association des Femmes Actives et Solidaires (AFASO)	Yaounde Cameroon	Mrs. Pauline Mounon	(237) 223 40 20	afasocm@yahoo.fr gtz-ssp.org@camnet.cm
Réseau National Ethique, Droit et VIH (REDS)	Yaounde Cameroon	Mr. Jean Marie Thalou (President)	(237) 220 53 65 (237) 220 59 62	redscm@yahoo.fr jmtalom@hotmail.com
Réseau Ivoirien des PVVIH (RIP+)	Abidjan Côte d'Ivoire	Mr. Boua Bi (President)	(225) 23 51 96 99	
Association Ruban Rouge	Abidjan Côte d'Ivoire	Mr. Ouattara Issa	(225) 23 50 49 27	ruban-rouge@ci.org
Association Virus Village	Abidjan Côte d'Ivoire	Mr. Boua Bi (President)	(225) 23 51 96 99	
Association Club des Amis	Abidjan Côte d'Ivoire	Ms. Kouame Tatiana (Secretary General)	(225) 21 24 43 79	cda_ci@yahoo.fr
Association Action Santé Plus	Abidjan Côte d'Ivoire	Mr. Désiré N'Da (President)	(225) 23 50 25 23	
Groupe d'Assistance de PVVIH et de Promotion Sociale (GAP+ PS)	Abidjan Côte d'Ivoire	Mr. Koffi Jeannot Kouadio	(225) 05 05 48 70 (225) 23 50 74 01	gap+ ps@ci.refer.org
Association Lumière Action	Abidjan Côte d'Ivoire	Mrs. Leiliane M'Boa (President)	(225) 24 39 73 12	lumaction@globeaccess.net

Organization Association	City/ Country	Contact person	Tel/Fax	E-mail
Association AMEPOUH	Abidjan Côte d'Ivoire	Mrs. Christine Ghoni (President)	(225) 23 51 98 74	amepower@yahoo.fr
Association Gabonaise d'Assistance et d'Action aux Séropositifs (AGASS)	Libreville Gabon	Mrs. Sidonie Siaka	(241) 74 87 17 (241) 76 80 00 (241) 73 43 65	hangoubadi@assala.com
Association WISDOM	Accra Ghana	Mr. Brandford Yeboah (President)	(223) 21 24 45 39	wisdom@yahoo.com
Society for Women against AIDS in Africa (SWAA)	Nouakchott Mauritania	Mrs. Sana Abass (Coordonator)	(222) 52 50 525 (222) 63 05 200 Fax : (222) 52 50 176	sanatijani@yahoo.fr
Association Out SIDA	Nouakchott Mauritania	Mr. Moulaye El Hacem (President)		

References

1. Angelina Moruah Domakyaare, HIV/AIDS and Human Rights, CHRAJ/Ghana
2. Comité national de lutte contre le SIDA et les IST - Burkina Faso : Cadre stratégique de lutte contre le VIH/SIDA 2001-2005
3. Edmund N'Delle (Dr.), Human Rights and HIV/AIDS in Ghana - a living testimony (CAPSDH-Ghana)
4. Appiah Stephen Afrane E.N., Infringement on the rights of people living with HIV/AIDS, any evidence in Ghana? Survey report
5. Ghana AIDS Commission, Ghana HIV/AIDS strategic framework 2001-2005
6. Ndala Musuamba Marie-Louise, Document de travail sur la politique en RD Congo en matière d'éthique, droit et VIH/SIDA
7. UNAIDS, AIDS in Africa country by country. Africa Development Forum 2000, AIDS: the greatest Leadership Challenge
8. UNAIDS, HIV/AIDS and human rights : international directives
9. Programme national de lutte contre le VIH/SIDA - Cameroun : Plan stratégique de lutte contre le VIH/SIDA 2000-2005
10. Programme National de Lutte contre le VIH/SIDA, les MST et la tuberculose (PNLS /MST /TUB) Côte d'Ivoire : Plan stratégique de lutte contre le VIH/SIDA 2000-2004
11. Programme national de lutte contre le VIH/SIDA/Mauritanie : Plan stratégique national de lutte contre le VIH/SIDA 2000-2002
12. Programme national de lutte contre le VIH/SIDA/Gabon : document de travail du PNLS
13. Revue Marchés Tropicaux (Spécial), Côte d'Ivoire, 15 décembre 2000
14. Réseau africain sur l'éthique, le droit et le VIH/SIDA/RD Congo : Rapport de la journée de réflexion sur les questions socio-culturelles, éthiques, et juridiques engendrées par l'infection à VIH/SIDA
15. Réseau africain sur l'Ethique, le droit et le VIH/SIDA : Actes de la consultation inter-pays/Dakar, Sénégal, 27 juin-1er juillet 1994
16. Sita Bamba et Michel R. Morissette : Rapport de consultation sur les aspects éthiques et juridiques liés à la discrimination
17. Talom J.M., Lumières sur le réseau sur l'éthique, le droit, et le VIH/SIDA - Cameroun
18. UNAIDS, Protocol for the identification of discrimination against people living with HIV
19. UNDP, Human Development Indicators, 2001

World AIDS Campaign
2002-2003
against stigma
and discrimination

"Lets stop expressing pity
rejection and fear of people
living with HIV/AIDS - We must
change the way we see but not
close our eyes".

Pierrette Adams, Singer and
UNDP Ambassador, Cote d'Ivoire

"To live better, we must accept".

Christine Gouhi,
Amepouh: Association of Women
Living with HIV/AIDS, Cote d'Ivoire



Joint United Nations Programme on HIV/AIDS

UNAIDS

UNICEF • UNDP • UNFPA • UNDCP
ILO • UNESCO • WHO • WORLD BANK



Joint United Nations Programme on HIV/AIDS

UNAIDS

UNICEF • UNDP • UNFPA • UNDCP
ILO • UNESCO • WHO • WORLD BANK

Inter-Country Team for West and Central Africa

04 B.P. 1900 Abidjan 04, Côte d'Ivoire
Tel.: (225) 22 40 44 01 / 22 40 44 11 / 22 40 43 95
Fax: (225) 22 40 44 09 / 22 40 44 13
E-mail: eip.onusida@aviso.ci
Web site: <http://www.onusida-aoc.org>