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Law, Ethics and AIDS in Sub-Saharan Africa Senegal as a Case Study

Charles Becker

CNRS, Dakar - Paris, Centre d'études africaines – École des Hautes Études en Sciences sociales

in memory of Gill Seidel († 2006)

Historians have paid scant attention to the health control regulations which express the relationship between the State, the law and health and which constitute the legal framework of interactions between political powers and the players in health systems – patients and their families, health professionals and associations responsible for health. In many West African countries the neglect of this field is today reflected in a lack of public health codes which should take into account the fundamental right of citizens to health. In an earlier article, I have stressed the need for historical research into these subjects in order to face current health challenges, to establish health codes and to instigate debate on ethical questions pertinent to accepting responsibility for the ill and for biomedical research.¹

The role of the social sciences in the training of health personnel in sub-Saharan African countries remains inadequate: sociology, history, geography and health economy remain the poor relations in the curriculum. The resulting deficit in skills explains, in part, the almost non-existence of ethical proceedings and debate on legal aspects of health. In addition, in the field of philosophy and of law itself, interest in health is paltry: in Africa these are new fields. Only a few recent initiatives allow one to hope that account will be taken of basic questions regarding health in sanitary conditions which are otherwise painted in very dark colours.

Faced with social science experts' lack of interest regarding health questions in Africa – especially evident in Francophone Africa – there has been an investment on the part of doctors regarding “social” and “cultural” questions raised by the new health problems. However, the quality of work carried out is far short of replying to the questions raised, wordings are often “naïve” and results unsatisfactory. AIDS in particular, a disease which is still branded as “social” or “a scourge”, but also tuberculosis and malaria have inspired studies – undertaken by researchers belonging to biomedical disciplines – whose methods and results have often been questionable.

The aim of this contribution is to suggest some basic principles for a history of AIDS in Senegal. It concentrates on the effects which resulted from the onset of this new disease and looks at initial developments in ethical thoughts and practices. Special attention will be paid to research carried out in the last twenty years by referring to an earlier study which

¹ Charles Becker, “Prolégomènes à une réflexion sur l'État colonial, le droit et la santé dans l'Ouest africain francophone”, in Issiaka Mandé & Blandine Stefanson (éds), *L'Afrique et la mondialisation : regards d'historiens / Africa and Globalization : The Historian's Perspective*. Paris, Bamako, AHA / Karthala / ASHIMA, 201-219. [version électronique : http://www.refer.sn/rds/article.php3?id_article=34]

stressed the permanent elements in the thinking and policies regarding sexually transmitted diseases and AIDS.¹

Several important questions, concerning the entire field of health, underlie this study: what are the origins of the “gulf” in ethical thinking between countries of the South and those of the North? How are these differences manifested today? What attempts were and are being made today to bridge this gap in southern countries? What are the obstacles faced? What processes should be given preference? By raising these questions I have attempted, in this historical study, to evoke the places and the means by which ethical questions slowly began to emerge. The AIDS situation in Senegal is exemplary from many points of view but it has, doubtless, brought about fewer changes in defining the role of the players in the health sector than has been the case in the North.

This study, firstly, proposes a comparison between the situations in the North and the South in the context of AIDS. Next, it looks at the answers suggested by Senegalese society to legal and ethical questions asked at the outbreak of AIDS. I will follow events such as the creation of the Ethical and Legal Committee within the National Multidisciplinary Committee for the Prevention of AIDS (CNPPS) up until the formation, in 2001, of the Senegalese Ethical Committee within the National Council for Health Research, by recalling other initiatives – sometimes tentative – which have marked these past two decades during which AIDS was the object of the scientific community’s close attention as well as that of other Senegalese community organisations. Finally, this study will propose that, as is the case for other health problems, the ways of accepting responsibility for AIDS (in a situation where there was no medication) and of research into the disease (more often than not undertaken by teams from the North who are far from always applying ethical principles acceptable to those in the South), need to be analysed within a framework of reflections on the relationships between the State, health and the law.

Health codification and development of ethics in the time of AIDS

In northern countries the AIDS epidemic has provoked strong social reactions and major changes regarding health codification and ethical thinking. It has been the subject of social and political debates which have brought about important legislative changes concerning the rights and duties of health professionals and patients. In France, the adoption of the law of 4 May 2002 pertaining to the rights of the patients and the quality of the health systems, may be seen as the result of debates entered into concerning the affair of contaminated blood. This law confirms the right of every individual to have his/her health protected. It stipulates that the “fundamental right to the protection of health must be put in place by every means available and must benefit everyone. Professionals, health establishments and networks, health insurance firms and all organisations which participate in prevention and care, as well as health authorities must contribute, together with the end users, to developing prevention, to guaranteeing equal access for each individual to the treatment required by his/her state of health and to ensuring the continuity of the treatment and the best health security possible”.²

In Africa, old diseases – whose immanent eradication and disappearance have been forecast – have reappeared and have become more formidable because of resistance to medications. Other diseases of forms of disease have appeared, creating a disturbing scenario

¹ Charles Becker et René Collignon, “A history of sexually transmitted diseases and AIDS in Senegal: Difficulties in accounting for social logics in health policy” in P.W. Setel, M. Lewis & M. Lyons (eds), *Histories of Sexually Transmitted Diseases and HIV/AIDS in Sub-Saharan Africa* (Westport, Greenwood Press, 1999), 65-96.

² *Code de la santé publique. Code de la famille et de l’aide sociale*, 17th édition, annotated by Jean-Michel De Forges, Didier Truchet, Jean Penneau, Georges Viala and Eric Fouassier (Paris, Dalloz, 2003), 2-3.

dominated by the AIDS epidemic. This epidemic is one of the major challenges of contemporary Africa. Millions of men, women and children are affected by the disease and have no access to medication which is, nevertheless, available: whilst scientific discoveries and past successes in biomedicine were “transferred” to former colonised populations in order to prolong life, in the case of AIDS, countries with weak resources and a decline in birth rate have been abandoned. The reasons for this need to be established and responsibility accepted.

Since the nineteenth century, many biomedical research projects have been undertaken in Senegal.¹ They have been responsible for many important discoveries particularly the perfecting of vaccines which have resulted in lengthening life expectancy and changes in demographic transition beyond Senegal alone. During the past decades – even before independence – there has been considerable development in research at the Faculty of Medicine at the University of Dakar often led by countries from the North, but with much local collaboration. Research undertaken in certain disciplines has been favoured. Although in a less exemplary way than has been the case in the North, AIDS has provoked ethical debate as well as advancement in biomedical practices.

General and specific ethical considerations regarding biomedical research in countries of the South occurred in the absence of appropriate health codification. The specific lack of thinking and debate on ethical questions can be seen as the result of a more fundamental gap. If, in countries in the North, there has been considerable development in reflection on ethical questions as evidenced in publications and debate which surrounded and continues to surround the revision of existent texts, the adoption of new measures and the overhaul of health regulations, Africa’s contribution to this work is minimal. Barely one per cent of the studies appearing in the data base *Medline* make reference to Africa. This figure demonstrates the lack of reflection on ethics and law in Africa. In addition, an examination of these references reveals that they are often texts written by northern researchers during or after their research in the South where they state the ethical principles for research in countries of the South where answers are provided for research challenges undertaken without respect to ethical principles. The position of ethical and legal questions in Senegal remains negligible, more so than in certain English speaking countries where contributions are more numerous. A marked contrast exists between the abundance of scientific work carried out in Senegal on HIV and AIDS² and the very small number of publications dealing with ethical and legal aspects.

A complementary approach reinforces this statement: if one were to look at the initiatives which have been undertaken during the course of the past decade, one would notice that the English speaking world is in first place. The contribution made by French researchers in meetings dealing with ethical questions has been small. English speakers play a dominant role in the setting up of networks for the formation and development of capacities created through the initiative of United Nations development agencies (UNDP, WHO, UNESCO, UNAIDS) in America (USAID, FHI) or those of England³. Canada also plays an important role, with the HIV/AIDS legal network “Aidslaw”⁴ which, unfortunately is little known in Francophone African countries. It was necessary to wait until May 2002 for the publication by the Agence nationale de recherche sur le sida (ANRS) of the “Charte d’éthique de la

¹ François Adam et Jean-Pierre Digoutte, 1896-1996. *Bibliographie analytique des travaux de l’Institut Pasteur de Dakar et des Pastoriens en Afrique de l’Ouest* (Dakar, IPD, 1997); René Collignon et Charles Becker, *Santé et population en Sénégal des origines à 1960. Bibliographie annotée* (Paris, INED, 1989); Charles Becker and René Collignon, “A history of sexually transmitted diseases and AIDS in Senegal”.

² Charles Becker, *La recherche sénégalaise et la prise en charge du sida. Leçons d’une revue de la littérature* (Dakar, Réser-Sida, Résédoc, CNLS & Population Council, 2000) <<http://www.aodl.org/becker.php>>.

³ See the IRD Deontology and Ethics Committee’s website (<http://www.ird.fr>) under the heading Paths of reflection, themes targeted, where the minutes of several meetings can be found.

⁴ <<http://www.aidslaw.ca>>

recherche dans les pays en développement”. In March 2004 the “Premières journées francophones d’éthique interculturelle” (First Francophone days of inter-cultural ethics) took place in Lyon. With the support of the European Community, a new initiative enabled the creation of the “Networking on Bioethics in Biomedical Research in Africa” (NEBRA), whose aim, for the first two years, consisted of identifying available resources and elaborating a programme to strengthen capacities.

These gaps must be considered in relation to the absence of reflection on research mechanisms and means of financing research in southern countries as well as “orientations” insisted upon by the promoters. Somewhat promoted by English speaking historians, the analyses which present Africa as a “laboratory” and the people included in the research as “guinea pigs” are recent and still rare¹.

Finally, the need to make the results of research available to the sick is far from being agreed upon by countries in the South. If one were to recall the appeal to transfer new therapies to the sick in countries of the South, an appeal made during the first conference “Social Sciences and AIDS in Africa” at the end of 1996, one is forced to admit that this is far from happening:

Such a political desire can not depend only on African states and their internal ability for mobilisation. It obviously also effects North/South relations and must precisely manifest itself in a refusal to accept a lasting installation of two types of AIDS: one in the North which will more or less stabilise itself and which will no longer be caught up in a diagnosis of death, the other in the South which will whose pandemics will continue to multiply as will announcements that it is an incurable disease. For this reason, the transfer to Africa of therapeutic treatment of AIDS is absolutely central. Whatever the difficulties of such a transfer, either financial or the medical follow-up of numerous African patients, one must react on the level of principles and admit the necessity which is both ethical and political. This is the price that African countries will have to pay in order to mobilise themselves to quell suspicions, which are widespread on the continent and which favour compromising prevention programmes, according to which AIDS constitutes for the North a way of stigmatising Africa or of unloading onto it the North’s own iniquities.²

Running through the question of access to therapy, are the legal and ethical questions of a more general nature: generally speaking, the small amount of progress made seems to be linked not only to the lack of political involvement in the epidemic but also to the feeble or absent reflection on the basic problem “State, health, right” which should lead to debates concerning the ethical treatment of the epidemic, the deontological aspects of the players actions and the rights of the people affected. How can one affirm today and in a more precise way, how can one in reality implement the right to health which is stated in the constitution of all nations and international organisations as well as the rights which are, more often than not, denied of people living with AIDS?

Senegalese society’s reply to ethical problems posed by AIDS

In many African countries involvement in the fight against AIDS at the highest level of political authority has, for a long time, been insufficient. Some of the reasons for past

¹ See the dossier “Les nouveaux cobayes de la recherche”, *La Recherche*, 342 (2001). Affirming, as some experts do, that “at the end of the test all those who were ill experienced some benefits” and that “the era of guinea pigs is over” (Christian Hervé, “L’époque du cobaye est finie”, in *Valeurs mutualistes*, 2002, 24 may be acceptable in the North but rings untrue in countries where access to care and to therapy remains a major challenge. See Jean-Baptiste Guiard-Schmid, “Accéder aux soins, un défi majeur pour les pays en développement”, *Transcriptase*, special issue, ANRS information, Durban 2000 (Paris, ANRS, 2000), 2-5.

² Jean-Pierre Dozon, “Des appropriations sociales et culturelles du sida”, in Becker *et al.*, *Vivre et penser le sida en Afrique*, 687-688.

inaction, not to say denial of the reality of the epidemic, are known.¹ It has taken twenty years for a general assembly of the United Nations to be devoted to this question and for more global action to be decided upon. In contrast, the study of two African countries —Uganda and Senegal— where, early in the struggle, the government engaged in action against AIDS has enabled the identification of certain factors which explain the relative success of the programmes undertaken:

A detailed analyses of the factors that led presidents Museveni and Diouf to become involved in the field of HIV/AIDS allows one to identify four central aspects of the guiding lines: (a) a motivated structure has emerged where those who are responsible have little to lose and everything to gain by becoming involved in the fight against HIV/AIDS; (b) those who are responsible have become involved in the fight on the basis of medical and scientific evidence; (c) it has become illegal for anyone holding a position in government not to become fully involved in the fight against AIDS; and (d) the main people responsible have become the pivots for the mobilisation of organisations in society. The political structure has been a determining element in each of the four factors but political outcomes have also been determined by the action of the community of funders.²

In Senegal, ethical thought in the health field is recent: its first institutional developments coincide with the creation of a multidisciplinary National Committee for the prevention of AIDS (CNPPS). Amongst the powers of the Committee determined by the decree of 2 February 1990, was the mission “to prepare the legislative and statutory measures for the prevention of AIDS”. According to the original text³ the consultative ethical and legal research group consisted of members of the limited CNPPS committee and of experts in the psychological, sociological, clinical, biological, legal, socio-behavioural and religious aspects of AIDS. It was charged with assessing the research projects into AIDS, with drawing up legal and statutory texts pertaining to AIDS and with checking on the ethical problems of the social aspects of the disease.

This sub-committee is, without doubt, one of the first in Africa, but little is known of its activities during the twelve years of its existence: its story remains to be told. It is important to collect accounts of its actual functioning as well as its dysfunctioning which has often been mentioned, particularly during the First National Forum on Research Into AIDS held in September 1999 and during the National Conference on health when it was insisted that there was a need to “re-energise the national “Ethical” committee of the national programme for the fight against AIDS so that it could examine and validate, on an ethical level, all the protocols for research”. The 2002-2006 strategic plan established by the National Council for the Fight against AIDS (CNLS) repeated this statement: it stated that its aim was “to strengthen the ethico-legal consultative committee” and defined three strategies:

- updating of ethical and legal norms pertaining to HIV/AIDS,
- re-energising the ethico-legal consultative committee,
- updating legal texts on prostitution.⁴

¹ Didier Fassin and Jean-Pierre Dozon Jean-Pierre, “Les États africains à l’épreuve du Sida”. *Politique Africaine*, 32 (1988), 79-85; Jean-Pierre Dozon and Didier Fassin, “Raison épidémiologique et raisons d’État. Les enjeux socio-politiques du Sida en Afrique”. *Sciences Sociales et Santé*, 7/1 (1989), 21-36.

² James Putzel, *Institutionalising an emergency response: HIV/AIDS and Governance in Uganda and Senegal. A Report submitted to the Department for International Development*, May 2003, iv. <<http://www.crisisstates.com/associated/HIV>>.

³ Decree 1291 of 2 February 1990, stating the creation of the National Multidisciplinary Committee for the Prevention of AIDS, a text which, like many others, has not been published in the *Journal Officiel de la République du Sénégal*.

⁴ Conseil national de lutte contre le sida, *Plan stratégique 2002-2006 de lutte contre le sida* (Dakar, CNLS, 2002), 39.

Historical enquiries amongst members of this internal committee would be useful in order to describe the past activities of this sub-group and to understand its relative silence. In fact, even if opinions were given by CNPPS officials before the completion of research undertaken within the framework of projects subsidised by countries of the North, it is not known whether these opinions, voiced by people who were themselves involved in this research, were biased and whether the recommendations were made with respect to the ethical principles during the different phases of their implementation. Besides, it is difficult to know how many of the numerous research projects undertaken by Senegalese researchers, were examined and discussed by the committee established for this purpose.

One of the reasons, mentioned above, for the success of the fight against AIDS in Senegal is the existence of a legal and statutory body on prostitution. Former measures as well as new ones put in place after independence have resulted in appropriate information and prevention, from the onset of AIDS, amongst social groups considered to be vulnerable and at risk and particularly amongst prostitutes. Measures taken have been characterised by a desire for “control”, as prostitution is seen as the medium for the transmission of HIV/AIDS. Within this framework, diverse scientific studies have been undertaken and groups monitored for the duration. As a corollary, efforts have been made to strengthen the statutory body but without any real results. These studies of groups of prostitutes have been significant. They continue today. They deserve to be better known and discussed more often from an ethical point of view. New studies on prostitutes and their clients as well as on the milieus for male prostitution have been undertaken or soon will be: it would be a good thing if real debate could be held on these topics.

One of the oldest initiatives with which Senegal has been associated is that of the African Network for Research Into AIDS (RARS) which organised an international workshop on the theme “Ethics, Humanity, Rights and AIDS in Africa” in Lagos in November 1991. The report from this workshop deserves to be reread in order to appreciate the gap that exists between the stated aims and the actual achievements within RARS. The aims were the following:

1. to formulate ethical directives concerning research into and treatment of AIDS and HIV in Africa;
2. to make the public more positively aware of the rights of the human being with regard to those living with HIV and AIDS in Africa;
3. to promote the rights of humankind in Africa in all fields linked to HIV infection and to AIDS by aiding understanding and promoting debate amongst those who are infected;
4. to protect the rights of women and children suffering from HIV and AIDS in Africa;
5. to identify and intervene in the main African at risk contexts;
6. to encourage a positive attitude concerning problems posed by the HIV infection and AIDS and to promote means of controlling the infection in Africa.¹

The UNDP played an important role by developing, under the aegis of the “HIV Programme and Development”, a regional project driven by Elizabeth Reid “HIV and Development for Sub-Saharan Africa” through whose initiative a network “Ethics, Law and HIV” was undertaken as early as 1993. The Intercountry Consultation from 27 June to 1 July 1994 was preceded by each country preparing documents. That of Senegal² shows the inadequacies of certain analysis which should be seen in relation to the epidemiological situation of the country. The immaturity of reflection on these themes is obvious, as is the case with contributions from other Francophone countries. This gathering drew up the “Dakar

¹ Réseau africain de recherche sur le sida, 1993, 2.

² PNUD/UNDP, *Consultation inter-pays du réseau africain sur l'éthique, le droit et le VIH, Dakar, 27 juin-1er juillet 1994* (Dakar, PNUD, 1995), 51-58.

Declaration” whose ten basic principles remain extremely relevant. It was followed by the creation of the “Ethics, Law, HIV/AIDS” network which, for several years, carried out important work in the English speaking countries, particularly South Africa, before ceasing its activities. Senegal has remained withdrawn despite pleas made to the Senegalese members of the network to coordinate the projects. The UNDP has also supported the development of a pan African network of people living with AIDS where ethical and legal problems have been discussed. The development of the network in Senegal appears to have been hampered, in part, by the desire for discretion amongst those involved (maintaining the anonymity of those who are infected) in a situation of low prevalence and the fear of stigmatisation of victims of HIV. The desired links between the two networks have been more or less close in certain countries, but have remained inadequate in Senegal.

An important event from an ethical point of view has been the debate involving the research undertaken by the ANRS in Africa and in Senegal. ACT-UP’s questioning of the research and studies carried out up to that time and the subsequent initiatives by associations of people living with HIV (PVVIH) have created conditions for debate which have put a stop to certain research. These debates are mentioned in different publications.¹ They have been at the root of a process initiated by ANRS, under the leadership of its director Michel Kazatchine, with which the players in the South have been associated and which has led to the adoption by this body of an “Ethical Charter for research in developing countries” in 2002, to which the IRD and the Pasteur Institute have subscribed.

The “VIH/sida et droits de l’homme en milieu médical sénégalais” (HIV/AIDS and the human rights in Senegalese medical milieu) forum held in July 2001 at the suggestion of the medical section of Amnesty International Senegal, allowed, for the first time, ethical reflection of a global nature on the practices of both local and foreign doctors and researchers in Senegal. The results of this meeting were reflected in the introduction to the report:

The results of stigmatisation are exacerbated because of the limits in accepting medical responsibility, the deterioration of the financial situation, (job loss, cost of medications, increase in hospitalisation) and the lack of support for infected and affected people.

Even if, in general, the care for those living with HIV is relatively good in Senegal, there have been reports of cases of abuse, discrimination, refusal of care, screening tests without informed permission from those affected and research carried out without taking into consideration the international norms contained mainly in the Helsinki declaration.

These practices are counter productive in terms of public health. By encouraging prejudice and stigmatisation they constitute a serious obstacle to prevention. Health officials are key players in this process: they are often best able to influence behaviour and to reduce the risk of transmission.

The abuses and absence of ethical laws are also found in a more general scenario: deficiencies in the health system, shortage of personnel and means, absence of an adequate legal system and especially of a genuine health code.

People, whatever their status, have the right to be treated equally – taking into account their specific needs (for women, children and those deprived of freedom) and whatever the facilities used (public, private, dispensary, prison or psychiatric hospital).²

Several recommendations were proposed by the Forum particularly with regards to strengthening the legal structures needed to protect those affected with HIV or those included in the research, to create or reinforce the examples of ethical thought and to put in place or reactivate an ethics committee into research with clear and transparent criteria for nomination which would look into research.

¹ Voir le dossier “Les nouveaux cobayes de la recherche”, *La Recherche*, 342 (2001), 28-39.

² Félix Atchadé, Ann Spencer *et al.*, *VIH/Sida et Droits de l’Homme en milieu médical sénégalais. Rapport d’un atelier tenu à Dakar, 18-19 juillet 2001* (Dakar, Amnesty International, 2003), 4. <<http://www.efai.org>>.

Other recent initiatives can be mentioned. In 1995 and 1996 Muslim and Catholic religious leaders met to discuss AIDS before jointly organising a seminar on “AIDS and religion” where ethical questions were raised¹. Recently the Medical Association has founded an ethics committee where questions relating to AIDS are regularly discussed. Non governmental organisations and associations have paid greater or lesser attention to ethical questions during their meetings, workshops and seminars held during the past decade. ENDA, SWAA, Réser-Sida and especially Synergy for Children can be mentioned as being closely associated with the organisation of the Amnesty International conference mentioned above and which contributed to the elaboration of the guide published by Alliance.² This work consists of a manual on the ethical and legal questions posed by the acceptance of responsibility for orphans and vulnerable children (5. Social Inclusion). Synergy for children has opened a voluntary and anonymous counselling and testing centre in Pikine-Guédiawaye where the child will be accompanied and where an “Ethic” commission has been established since the conception of the project.

For their part, the PVVIH associations have obtained different forms of support –particularly from UNDP, Act-Up, and ENDA– for the strengthening of their abilities, without the ethical and legal aspects necessarily being considered as priorities. ECI (Enhancing Care Initiative) is a collaborative project between Senegalese researchers and the University of Harvard involving studies on ethical matters. One of them takes into consideration a study made by practising doctors on the practices and ethical problems encountered in the face of AIDS.

Mention can also be made of the conference held at Sali “Social Sciences and AIDS in Africa”³ where several studies on ethics and AIDS were presented: however, these studies have barely been read or followed up. In addition, in 1999, the Forum on Research into AIDS made firm recommendations with a view to reinforcing debate on ethical questions in biomedical research as well as in the field of accepting responsibility for AIDS. Finally, a not negligible position is held by the NGO Africa Consultants International (ACI) which has developed conscientisation programmes over the past few years particularly amongst parliamentarians and opinion makers. Studies have thus been undertaken to understand better the present legal situation by identifying its inadequacies and by making suggestions for its improvement.⁴ However, the implementation of the proposed policies has encountered many difficulties.

Recently, several theses in the Faculty of Medicine at Dakar have paid attention to ethical issues. Particular mention can be made of Lamine Fall’s research⁵ on confidentiality as well as other less specific thesis. However, these works are rare. Information relating to

¹ During this conference in 1997, Amsatou Sow Sidibé presented a remarkable paper which has recently been published. See Amsatou Sow Sidibé, “Le droit à l’épreuve du VIH”, *Psychopathologie africaine*, 31/2 (2001-2002), 191-220.

² *Bâtissons l’espoir: notes thématiques pour l’Afrique. Ressources pour les communautés soutenant les orphelins et enfants vulnérables*. 1. Vue d’ensemble. 2. Education. 3. Santé et nutrition. 4. Soutien psychosocial. 5. Inclusion sociale. 6. Renforcement économique. (Londres, Alliance Internationale contre le VIH-Sida, 2003), 6 volumes

³ Charles, Becker, Jean-Pierre Dozon, Christine Obbo et Moriba Touré (éds) *Vivre et penser le sida en Afrique / Experiencing and understanding AIDS in Africa* (Paris, Karthala-Codesria-IRD, 1999).

⁴ Jérôme Bougazelli, *VIH/Sida et prostitution: ambiguïtés et obsolescence des textes sur la prostitution au Sénégal. Document de travail* (Dakar, ACI, 2002); Jérôme Bougazelli et Louise Fatim Dia, *Questions prioritaires en matière de législation sur le VIH/Sida au Sénégal. Document de travail* (Dakar, ACI, Réseau santé, sida et population du CONGAD, Réseau des parlementaires sur la population et le développement, 2000).

⁵ Lamine Fall, *État des lieux de la confidentialité partagée dans l’infection à VIH/Sida à Dakar* (Dakar, UCAD, Faculté de médecine de pharmacie et d’odonto-stomatologie, 2000).

diverse ethical problems is contained in the collective work on the Senegalese initiative for access to antiretrovirals.¹

In April 2003 the Senegalese network “Law, Ethics and Health” was created and the first degree in advanced studies in Francophone Africa, the law of health, has been offered since January 2004. Within this framework, research and teaching on ethical questions relating to AIDS have been on offer. The Agence universitaire francophone (Francophone University Agency) has actively supported these initiatives within the framework of the new Francophone network for law in health, founded in July 2003 and operating since November 2003.

In 2003 a “Legal and Ethical” centre was opened at Saint-Louis, an combined initiative of the teachers/researchers of the Gaston Berger University in Saint-Louis and Jurisaid, an association with an international vocation founded by Ousmane Sané, a Senegalese lawyer who was the first president of the ethical and legal group of the CNPPS.

Until these recent initiatives, the reservations shown by university staff regarding ethical issues has been obvious as has the paucity of their research. With the exception of a few articles, lawyers have barely been involved in ethical thought. Nor has the education “milieu”, a factor which explains the small number of text books of quality. An analysis of existing youth-orientated publications allows one to evaluate the reflection in the field of ethics.

The slow emergence of the law and ethics of health in Senegal

The scope of this reflection can be broadened by recalling the creation and development of the National Council for Health Research (CNRS) as an authority regarding ethical evaluation. It is interesting to note the position that AIDS occupied in the development of this authority. Mention will also be made of the on-going discussions concerning the competencies of this new institution and the future of the former ethical and legal commission of the CNPPS.

Towards the middle of the 1990s, Senegal adopted a new health policy that was marked by the adoption of a national programme of health development (PNDS), which resulted from the amalgamation of departmental and regional research programmes and the central service. In this way strategic trends for health development were defined including the development of research and particularly operational research concerning the most disadvantaged population groups in matters of health. In 1998 the Ministry of Health was restructured and a Department of Study, Research and Training (DERF) was created with the aim of lending technical support to departments and services undertaking research and to coordinate all operational research activities.

After a preliminary study of the needs and priorities for research into health in Senegal, a “National Plan for Research into Health” was adopted in 2001. An efficient and supple tool, this plan was submitted for re-evaluation and readjustment at the end of March 2004.

The establishment of the Ethics Committee took place against this background. The creation of an ethics authority was a requirement imposed on all member countries by WHO, but also met an international recommendation which made this a condition for the granting of funding for research projects. The Pasteur Institute in Dakar, which had had an ethics

¹ Alice Desclaux, Isabelle Lanièce, Ibra Ndoye et Bernard Taverne (éds), 2002, *L'initiative sénégalaise d'accès aux médicaments antirétroviraux. Analyses économiques, sociales, comportementales et médicales* (Paris, ANRS, 2002) <<http://www.anrs.fr/index.php/article/articleview/1008/1/317>>.

committee since 1955¹ helped the Ministry of Health and Prevention to put its own committee in place. After several meetings and following the recommendations of the national annual meeting on health (4-5 July 2000), the project submitted to the Ministry of Health resulted in the creation and the organisation of the National Council for Research into Health (CNRS) by the decree 1422 of 2 March 2001 which made a distinction between a scientific authority and an ethics authority. The new decree 3224 of 17 March 2004 modified the organisation of the CNRS which henceforth amalgamated the two authorities charged with the scientific and ethical evaluation of research projects into health undertaken in Senegal. The ethics committee functioned autonomously only for a short period, under the direct responsibility of the presidency and with the support of the Ministry of Health.

If many research projects were undertaken in Senegal, not all met the priorities identified by the Ministry of Health. It was for this reason that authorities were established by law in order to bring together Health Ministry officials and researchers so to coordinated research into health at a national level. These authorities consisted of members of the Ministry of Health, other ministries involved in health, research institutes, the WHO, local communities, associations and people who were chosen because of their expertise.

According to the decree of 2001, the CNRS is a national consultative organisation whose function is to advise the Minister of Health on research matters and to keep a watch over the ethical principles. The new decree of 2004 reformulated the powers of the CNRS by strengthening its ethical authority. It was charged with advising the Minister of Health on research matters, watching over the scientific quality of research projects into health, ensuring respect for ethical and legal principles in the field of health research, initiating and developing thinking into ethical and legal aspects which arouse from research procedures in health matters and making the researchers aware of the importance of ethics so as to guarantee an even balance between intellectual freedom and duty vis-à-vis society. This committee's secretariat was housed in DERF. At regional level, the district surgeon was put in charge of following up research carried out in the area under his control.

Initially the deliberations of the ethics committee of the CNRS were based on the minutes of meetings of the scientific committee. The means of examining the protocols was that of the scientific committee, with the remarks of this committee being taken into account. Subsequently all the members of the CNRS examined the protocols, in many cases insisting that protocols which had been submitted be reformulated or rewritten.

Between December 2000 and January 2004, 125 protocols were submitted to the CNRS, 17 of which concerned research into either AIDS or hepatitis. Much of the research which was underway and which had been started before the creation of the CNRS has not been examined even today. This research, often financed by Northern countries, was doubtless often the subject of the authorities' or internal ethics committees' opinions which were not imparted to the CNRS.

In the absence of legal or statutory documents concerning the protection of those participating in the research, the observations regarding benefits and risks, informed consent and confidentiality were often mentioned in the protocols in a cursory way, if they were mentioned at all. Reference to basic laws recognised at international level (Helsinki, Manila, WMA) is rare. As far as Senegal was concerned, one of the only laws is the Dakar Declaration of the "Ethics, Law and HIV" network where research is mentioned in a clear but incomplete way.

The experience of the Senegalese Ethics Committee and the discussions which took place there bear witness to the difficulties which researchers face. Even if the protocols were

¹ The internal ethics committee at the Pasteur Institute in Dakar was disestablished following the creation of the CNRS which the members of the Institute strongly supported from its inception.

submitted by renowned research teams or institutions from the North they generally contained ethical considerations which were vague or generalised. It is difficult to understand how this type of protocol could have been validated by ethics committees in the North to whom it appears they had been initially submitted. It has been shown that, in the case of multicentred protocols, the documents submitted often contain only those sections which are the broadest and the most multicentred and whose overall philosophy and general aims need to be exposed and the ethical principles communicated in their entirety to the national ethics committee.

The debates of the Senegalese ethic committee have underlined the need for a genuine monitoring of research protocols submitted before the creation of this institution as well as the need for clarification of the committee's competence, in the case of ethical problems being raised during the carrying out of a protocol which has already been started.

It is important that a more open collaboration between the North and the South be introduced in the areas of training and information exchange so that debate on ethical questions can be developed in Senegal and in Africa as it is elsewhere.

The ethics committee has often raised the problem of research being carried out in on site "laboratories". Many research projects have been and continue to be carried out in sites which are favoured by teams and by research institutions. The term "guinea pig" has sometimes been used in this regard when referring to a dossier published in 2001 by *La Recherche*.¹ Members of the ethics committee have requested that debate be begun regarding the "sites" for multiple research and the problems experienced by "over utilisation" of the same people or the same populations. Their participation in simultaneous or successive studies could, indeed, bias the findings without mentioning the inconveniences experienced to the groups involved,

The ethics committee has also raised the question of follow-up to tests (therapy and vaccinations) and their effects. Cases have been mentioned where the improvement of a product has not been monitored after it was first made available to those who had participated in the research. It would be useful to consider lawsuits in cases where tests had failed or had caused more or less serious harm to those involved. Re-referral to the regulations – which do not exist in the majority of countries of the South – with the aim of avoiding possible compensation seems to be the norm. Such a situation is unsatisfactory and calls for in-depth debate.

Conclusions

In the case of Senegal, elsewhere labelled as a success story in the fight against AIDS, historical analyses has shown that the debates concerning ethical questions remain short of the challenge posed by the epidemic.

As we have shown in our study of the history of STDs in Senegal² health policies established during the colonial era reveal an ambiguous relation between demographic topics (population growth, maintaining health so as to enhance the value of the colonies) and health topics (fight against venereal diseases). We note the constancy of some trends particularly those which confer the status of "social scourge" on certain diseases. Insofar as they compromised the desired population growth but also where they were more difficult to "control" than other diseases, these diseases were classified separately and were treated differently. Similar phenomena were observed during AIDS epidemic as is shown by the legal mechanisms aimed at ensuring the "control of at risk groups" at the risk of causing stigmatisation for those living with the virus.

¹ "Les nouveaux cobayes de la recherche", *La Recherche*, 342 (2001), 28-39.

² Becker et Collignon, "A history of sexually transmitted diseases and AIDS in Senegal" (see above footnote 2).

Since the end of the last century, the “fight” against STDs and against diseases which have to be declared has been marked by a tendency to globalisation and by a desire for control and eradication through the authority of doctors. International campaigns to control the birth rate make use of similar methods. In both cases, contradictions can be seen between the voluntary policies of the authorities and the point of view of the social players whom the authorities forget to consult when they are elaborating health programmes. New demands concerning the rights of persons are slowly asserting themselves as a result.

The need to develop networks, authorities and discussion groups which reflect on ethical questions raised by health developments and research programmes which are associated with them has become paramount. This ethical reflection should result in the installation of legal bodies which will allow the management of development and research concerning AIDS and that of health in general. These laws should consult all ethical questions pertaining to health if they wish to respond to current health stakes in Africa.

For a long time research has been possible without ethics committees and without true debate. This situation has changed. Recent initiatives by researchers, law makers, politicians, doctors and their patients reveal the importance of ethical thought at the very heart of health practices. On this point, we concur with James Putzel who, in his study of the fight against AIDS in Senegal and Uganda, notes:

... the need for more explicit attention to the ethical dimension of research, as much academic as clinical, into HIV/AIDS. Donors should pay attention to this when they finance research. They must also help developing countries set up a system of surveillance and engender respect for ethical norms in the work carried out under their jurisdiction.¹

Discussions concerning the ethics of health have barely begun. The results of research are far from being made available to patients in the South and they are far from having access to the care which they need. The demands of justice and ethics must be more vehemently and more precisely affirmed through appropriate legal bodies and community programmes. Such initiatives should allow more resolute participation on the part of the involved social players and the international community so as to ensure the right to life in an Africa weakened by AIDS.

(translated from the French by Carole Beckett)

¹ Putzel, *Institutionalising an emergency response*, 54.