The HIV/AIDS Epidemic in Sub-Saharan Africa in a Historical Perspective

Edited by

Philippe Denis and Charles Becker

Online edition

Réseau sénégalais “Droit, éthique, santé” / Senegalese Network “Law, Ethics, Health”

October 2006
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Note and acknowledgments

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• the Sinomlando Centre for Oral History and Memory Work in Africa, University of KwaZulu-Natal
  http://www.ukzn.ac.za/sorat/sinomlando

• the Health Economics and HIV/AIDS Research Division, University of KwaZulu-Natal
  http://www.heard.org.za

• the Crisis States Research Centre, Department of Development Studies, London School of Economics
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Cover Illustration

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Chantez la mémoire des morts par amour
le chant qui éblouit le visage des orphelins
écoutant une clameur inouïe
lumineuse, vivifiante!

Sing the memory of the dead by love,
the song which dazzles the face of orphans
listening to an unheard, vivifying
luminous clamour!

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Contributors

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Foreword

Philippe Denis and Charles Becker

This volume stems from a conference organized by the Chaire d’études africaines of the University of Louvain at Louvain-la-Neuve, Belgium from 11 to 13 March, 2004. Eleven of the chapters consist of reworked papers presented at the conference. The other articles were requested from their authors during the following months.

The contributors come from countries as divergent as South Africa, the Congo, Cameroon, Senegal, France, the United Kingdom and the United States. Whether they live there or have carried out their work there, all of the authors have an intimate knowledge of Africa combined with a personal interest in the AIDS issue. The fact that the studies included in this present volume equally concern English-speaking and French-speaking Africa is worthy of mention. Cultural and intellectual barriers continue to separate these two parts of the African continent. In order to facilitate a greater exchange of ideas, the decision was taken to publish the volume in both languages. The French version was published simultaneously by Academia-Bruylant (Louvain-la-Neuve) and Karthala (Paris) in October 2006. The English version is published on line.

We would like to express our thanks to the Chaire d’études africaines at the University of Louvain and the National Research Foundation of South Africa who financed the conference at Louvain-la-Neuve as well as this publication. Our gratitude is also due to Carole Beckett who translated the texts originally written in French.

We dedicate this book to all those, men, women and children who are afflicted with the AIDS virus, in Africa or elsewhere. Their individual and collective stories need to be told and with empathy and respect, bearing in mind the social and cultural context which give them meaning. It is their voice, not yet sufficiently listened to by historians, that we wish to make heard so that it may open up channels towards a future.

October 2006
Part One

Introduction
Towards a Social History of HIV/AIDS in Sub-Saharan Africa

Philippe Denis

University of KwaZulu-Natal

The aim of this volume is to initiate a dialogue between historians and experts in other disciplines such as economics, sociology, epidemiology and the science of development on the history of AIDS in sub-Saharan Africa\(^1\). The articles published here retrace, in overviews of the situation or in case studies, the spacio-temporal origin of the epidemic. Many of them make use of oral history techniques.

Particular attention has been paid to issues of chronology and periodisation. The intention is to approach AIDS in sub-Saharan Africa as an historical fact. The epidemic is not a recent as supposed, but, in many aspects, it is an unrecognized event. The question of the recentness of AIDS lies at the heart of the historical problem which this book aims at developing.

Another challenge is to view AIDS as a multidimensional event rather than as a purely biomedical one. The epidemic has unfolded in a socio-economic, political and cultural context which explains and situates it at the same time. The articles published in this volume reconstruct, sometimes in great detail, the framework of events and the perceptions and beliefs concerning the epidemic. Reference is made to the epidemiological history of AIDS but greater emphasis is placed on its social and cultural history.

The fifteen contributors come from sub-Saharan Africa, Europe and North America. Half wrote in French, the other half in English. A third are professional historians. The remainder, from disciplines such as anthropology, sociology, economy, epidemiology, medicine or development sciences, are not historians but have agreed to review the subjects of study with which they are familiar from an historical point of view. Eleven of these authors participated in the conference “The HIV-AIDS epidemic in sub-Saharan African in a historical perspective” held in Louvain-la-Neuve in Belgium, from the 11 to 13 March 2004. The remainder contacted the editors in the months following the conference.

This book covers the four large regions of sub-Saharan Africa: West Africa, Central Africa, East Africa and Southern Africa. Coverage by country is, on the other hand, somewhat unequal. It was not possible to include works on Portuguese speaking Africa or on that done in the Horn of Africa. On the other hand, greater proportional weighting is given to South Africa. In absolute figures, this country has the highest number of HIV positive people in the world. Thanks to its universities, its centres of research and its medical infrastructures it is also the African country which, for the past ten years, has generated the most work on AIDS, often in collaboration with European or North American partners.

\(^1\) The countries of North Africa where the level of those who are seropositive is comparable to that in France have been excluded from the field of study. For an idea of the AIDS epidemic in North Africa, see Jeanne-Marie Amat-Roze, *L’infection à VIH/sida en Afrique subsaharienne, propos géographiques*, Hérodote, 111 (4e trimester 2003), 121-125.
The past in the present

In 1989, the medical historian Mirko Grmek asked the question, in a pioneering work, whether AIDS, whose clinical symptoms had been described eight years earlier, was a new disease. Yes, he answered, for it was the first time in history that a disease without specific symptoms and with no trace of organic lesions, certainly at first sight, had made its appearance. The speed with which it spread was also without precedent. On the other hand, he added, AIDS was not new for it had been present, even if people were not aware of the fact, in humankind for several generations.2

Significantly, L'Histoire du sida devoted very little space to Africa3. It was only with reference to the origin of AIDS, hotly discussed at the time, that the African continent was mentioned. At the end of the 1980s, epidemiologists certainly acknowledged the existence of a second type of epidemic, which had its origin in central Africa and whose form of transmission was mainly heterosexual. But for Grmek as for the majority of AIDS historians of the time, what was important was to understand an epidemic threatening the very foundations of their own society, that is to say European and North American societies. The notion that AIDS was an even greater threat to developing countries had apparently not crossed their minds. Likewise, the collective work by Elizabeth Fee and Daniel Fox entitled AIDS: The Burden of History4, the article by the historian Charles Rosenberg in the journal Daedalus the following year on “AIDS in historical perspective”5 and the articles collected and published by Virginia Berridge and Philip Strong in Cambridge in 1993 under the title AIDS and contemporary history6 all allocate a small part to Africa. At the turn of the decade, studies such as that of Marc Dawson on the comparative history of syphilis and AIDS in East Africa7 or that of Randall Packard and Paul Epstein on the evolution of interpretative models for AIDS in Africa8 remain relatively exceptional.

Fifteen years later the importance of historical reflection on AIDS in Africa has become more evident. The first, most obvious, reason is the lightning speed with which the epidemic has spread throughout the world in general and Africa in particular. Some forty-five million people are HIV-positive, as I write these lines, 70% of whom are in sub-Saharan Africa, a region in which, I must emphasize, a mere 10% of the world’s population resides. Since the beginning of this century, AIDS in Africa has become a global challenge, a fact which is borne out by the vast sums of money which have been invested by international organizations and pharmaceutical. The awareness of the existence of an AIDS epidemic in sub-Saharan Africa goes back to 1983. Without mentioning the proto-history of AIDS which began

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2 Mirko D. Grmek, Histoire du Sida. Début et origine d’une pandémie actuelle (Paris, Payot, 3rd ed. 1995), 18. In the postscript of the third edition of his book, Grmek suggests that diseases such as AIDS which exist in the population before they are conceptualized as nosological entities be called “emergent” rather than “new”.

3 This is true also of the second and third editions which were reviewed and updated. The remark can also be applied to l’Histoire de la recherche sur le sida by Bernard Seytre (Collection “Que sais-je” N° 3024, Paris, PUF, 1995).


towards the end of the 1950s, if not earlier, the epidemic has been in existence for more than twenty years in Africa and its history needs to be documented and studied. In 1989, Mirko Grmek stunned his readers by daring to write the history of an epidemic which had just been declared9. Today, the historical dimension of the phenomenon is indisputable even though the political, economic and social stakes involved in a history of the epidemic are far from being agreed upon by the various groups involved in the fight against AIDS.

At the end of the 1980s and the beginning of the 1990s “a new consensus” (Charles Rosenberg) emerged amongst researchers on the necessity of combining biomedical and social points of view in the study of AIDS10. Once the mechanisms for the transmission of infectious agents are identified, the forms of social organization and the cultural practices which favour their diffusion need to be understood. It would be useless to try and ignore the social dimension of epidemics whether they be old diseases such as syphilis or tuberculosis or new ones such as AIDS, Ebola or SARS. International conferences on AIDS, which have taken place at regular intervals since 1985, demonstrate the growing importance of human sciences in the study of AIDS, a topic that virologists and medical doctors tended to monopolize during the early stages of the epidemic. During the past decade there has been a growth in anthropological, sociological, geographical, economical and political science studies on AIDS in Africa, as has been shown, along with others, by the collective conference proceedings from Sali Portudal (Senegal) “AIDS and social sciences in Africa” in 199611 and the volume published following the conference at Champaign-Urbana (United States) on “HIV and AIDS in Africa: beyond epidemiology” in 1999.12

Nevertheless, it is true, as Ezekiel Kalipeni and his colleagues have remarked,13 that the biomedical paradigm continues to dominate research into AIDS. Since the end of the 1980s, authors such as Jean-Pierre Dozon, Didier Fassin, Gill Seidel and Laurent Vidal have gone through ordinary epidemiological discourse with a fine tooth comb.14 Under the pen of doctors, epidemiologists and sometimes even experts in the human sciences, the so-called sexual promiscuity of Africans – to which I shall return – has been presented as the main cause for the spread of AIDS in Africa, as if HIV spreads in direct proportion to the number of sexual partners of its carriers. The majority of prevention programmes are based on models which judge the spread of HIV to be the result of at risk behaviour and the refusal on the part of the individuals in question to adopt supposedly rational sexual behaviour. Certainly there are many doctors and epidemiologists who take the epidemic’s social context into account

13 Ibid., 4.
and, as a result, adopt a more flexible view towards sexual practices and social change. But it is not their work nor that of their human science colleagues which head the list of priorities of organizations which fund research. It should be noted that research into AIDS is overwhelmingly western. The voice of African researchers who denounce the ethnocentrism of specialist discourse battles to make itself heard.\footnote{See for instance Collins Airhihenbuwa, \textit{Health and culture: Beyond the western paradigm} (Thousand Oaks, CA, Sage Publications, 1995); “Of Culture and Multiverse: Renouncing the ‘Universal Truth’” \textit{Health. Journal of Health Education}, 30 (1999), 267-273.}

It is in this situation that the importance of inaugurating a history of AIDS is measured. In effect, AIDS lies within the scope of a social, political and cultural history which precede and include it. In this context, Didier Fassin denounces a “decontextualized” reading of AIDS which limits itself to a description of the sexual practices of the potential carriers of the virus or to the identification of the cultural phenomena which favour the spread of the infection\footnote{Didier Fassin, “Crise épidémiologique et crise sociale”, in D. Fassin (ed), \textit{Afflictions. L’Afrique du Sud de l’apartheid du sida} (Paris, Karthala, 2004), 11.}

The social practices which prevention and treatment policies consider are not static. They bear the weight of history. AIDS develops in a territory which, for generations, has been marked by gender questions, political relations, class conflicts and racial tensions which determine or, at the very least, explain the particular paths which the epidemic follows. As Helen Schneider has suggested, in order to get into the epidemic’s mind one must read “the past in the present”\footnote{Helen Schneider, “Le passé dans le présent. Épidémiologie de l’inégalité face au sida et politiques de justice sociale”, in Fassin (ed), \textit{Afflictions}, 75-110. This expression is also to be found in the writing of Hansjörg Dilger, « Sexuality, AIDS, and the Lures of Modernity : Reflexivity and Morality among Young People in Rural Tanzania”, \textit{Medical Anthropology}, 22 (2003), 32.}

This remark is applied to South Africa but it can be used for the whole of the African continent. How, for example, can the high level of sexual violence in Southern Africa, an important factor in the transmission of HIV, be explained without taking into account the history of migrant labour which, under colonial rule and later under apartheid, broke up traditional family life and drove men, humiliated by their loss of social and economic power, to exert their domination over women’s bodies? In this context, Didier Fassin speaks of the “social condition” of AIDS. He distinguishes three aspects of this reality with reference to South Africa: socio-economic inequality, violence and migration.\footnote{Didier Fassin, “L’incorporation de l’inégalité. Condition sociale et expérience historique dans le post-apartheid », in Fassin (ed), \textit{Afflictions}, 30-37.}

Another new perspective is offered by the history of epidemics and of sexually transmitted diseases, a topic to which Mirko Grmek returns in the third edition of his work which appeared in 1995. “One can never say often enough”, he writes, “to what extent AIDS is different from all the other previously known illnesses and this as much by reason of its pathogenic mechanisms and certain epidemiological characteristics as by its medical conceptualization”. As is the case in the first edition of his book, Grmek speaks as a doctor but nevertheless, he does not neglect the social and cultural aspects of the disease. “The historian still has his say concerning psychological reactions and the effectiveness of social measures”, he adds. “Historical studies teach us, for example, that collective actions against scourges can only have lasting results if there is simultaneous recourse to medical intervention and social measures.”\footnote{Grmek, \textit{Histoire du sida}, 3e edition, 1995, 353-354.}

The comparison with other epidemics which have struck humankind, writes Gilles Bibeau, shows that “the prejudices and the research of the scapegoats reappear as soon as silence is no longer possible, as soon as the balance between individual and collective rights is threatened, as soon as human reactions to the threat of infection show what appears to be a limited repertoire.”\footnote{Gilles Bibeau and Ruth Murbach, “Déconstruire l’univers du sida”, \textit{Anthropologie et Sociétés}, 15/2-3 (1991), 8.}
his colleagues which was devoted to the history of sexually transmitted diseases and to AIDS in nine sub-Saharan African countries\textsuperscript{21} continues along the same lines, “For the most part, the novelty of AIDS is illusionary”, writes Setel. “Its roots go as far back as the processes of cultural change which the colonial experience deeply carved over a long time.”\textsuperscript{22} Along the same lines are the studies of Howard Phillips, an expert on the history of Spanish flu\textsuperscript{23} and Shula Marks, another South African historian,\textsuperscript{24} which were presented at the conference “AIDS in Context” in Johannesburg in April 2001. Both disclose important continuities between the colonial and contemporary eras in the development of the social management of epidemics. It is therefore necessary to clarify Grmek reply concerning the novelty of AIDS. From the standpoint of the vulnerability of populations to the disease and social responses to the epidemics, AIDS is nothing new. But, adds Phillips, despite this, it consists of several distinctive traits: its slow development (due to the long incubation period of the virus) and, as a result, its greater diffusion, the globalization of the fight against the disease and, finally, in South Africa but probably elsewhere as well, the effect of the rights of humankind on the response to the disease.\textsuperscript{25} The articles by Myron Echenberg and Benedict Carton which are contained in this volume continue this discussion of the specificity of AIDS in the history of epidemics. The study by Elizabeth Colson, an anthropologist who has spent fifty years observing and describing the way of life of inhabitants of the Gwembe Valley in Zambia, also makes an important contribution to the history of AIDS by demonstrating how traditional modes of solidarity and resistance in this region were maintained when the new epidemic appeared.

\textbf{Interdisciplinary work}

The aim of this book is to encourage, by means of a resolutely interdisciplinary and multinational approach, the thought that AIDS is an historical fact in sub-Saharan Africa. North African countries, where levels of HIV prevalence comparable to those in Europe are seen\textsuperscript{26}, have been excluded from the field of study. The fifteen contributors come from sub-Saharan Africa, Europe and North America. A third are professional historians. The remainder, from disciplines such as anthropology, sociology, economy, epidemiology, medicine or development sciences, are not historians but have agreed to review the subjects of study with which they are familiar from an historical point of view. Eleven of these authors participated in the conference “The HIV-AIDS epidemic in sub-Saharan African in a historical perspective” held in Louvain-la-Neuve in Belgium, from the 11 to 13 March 2004. The remainder contacted the editors in the months following the conference.

This book covers the four large regions of sub-Saharan Africa: West Africa, Central Africa, East Africa and Southern Africa. Coverage by country is, on the other hand, somewhat unequal. It was not possible to include works on Portuguese speaking Africa or on that done in the Horn of Africa. On the other hand, greater proportional weighting is given to

\textsuperscript{22} Ibid., 6.
\textsuperscript{26} For a first glance of the AIDS epidemic in North Africa see Jeanne-Marie Amat-Roze “L’infection de VIH/sida en Afrique sub-saharienne, propos géographiques”, \textit{Hérodote}, III (4e trimester 2003), 121-125.
South Africa. In absolute figures, this country has the highest number of HIV positive people in the world. Thanks to its universities, its centres of research and its medical infrastructures it is also the African country which, for the past ten years, has generated the most work on AIDS, often in collaboration with European or North American partners.

The works mentioned above, particularly that of Philip Setel and his colleagues, of the historians who participated in the conference “AIDS in context” in Johannesburg and of the Franco-South African working group coordinated by Didier Fassin, are decided forerunners in the field of research into the history of AIDS in sub-Saharan Africa. The articles which have been included in this book make frequent reference to them. But many questions relating to the origin and the spatiotemporal development of the epidemic remain without answers. We hope that, because of its comparative and interdisciplinary nature, this book will throw new light on these subjects.

An African epidemic

Why is it that the African continent is marked, and so extensively, by AIDS? This burning question must be asked. It is true that the global epidemiological situation is undergoing changes. The distance which separates Asia from Africa will perhaps narrow in future decades. Meanwhile, the problem remains. Why is it that, by a cruel stroke of irony, the African continent which is already in a disadvantaged position, sees its chances of development compromised even more by an epidemic which is decimating its active forces and puts its fragile medical and social infrastructures under unbearable strains? A similar question can be asked concerning South Africa: having barely escaped apartheid, this young democracy now finds itself confronting another evil, even more insidious, as if it didn’t need all its strength to overcome the three centuries of colonization and discrimination.

In their contribution to this volume, Alex de Waal and Alan Whiteside do not hesitate to state that the AIDS epidemic, when compared to others which have struck humanity in past centuries, is an historic event without precedent. Historians, amongst whom we include Myron Echenberg and Benedict Carton, arrive at conclusions which are less clear cut. If one concentrates on the infectious agent’s modes of transmissions and on medical, political and cultural responses an impression of continuity prevails. De Waal and Whiteside rely on statistical evidence: life expectancy, mortality, number of orphans. According to them the demographic impact of AIDS exceeds that of other epidemics, less from the number of deaths at any given moment – from this aspect, the Great Plague or the Spanish flu epidemic are comparable to AIDS when it comes to the percentage of the population affected – than in terms of the death rate in a given age group. In years to come, the effect of the disease on the most affected populations will be debilitating. In the seven countries where the average rate of HIV prevalence in adults who are sexually active exceeds 20%, the projections for the 2010-2015 period are terrifying: number of deaths multiplied by three, life expectancy reduced to the age of thirty, level of infant mortality almost doubled. All these countries, namely South Africa, Botswana, Lesotho, Namibia, Zimbabwe, Zambia and Kenya are in Africa. According to de Waal and Whiteside, more extensive use of anti-retroviral treatments will alleviate certain sufferings, but will not alter the course of the epidemic.

The question of the origins of AIDS, although independent of the seriousness of the epidemic in Africa, is ideologically and politically linked to it. In her contribution to the present volume, Anne Buvé states that the hypothesis most commonly accepted by virologists is that of a zoonosis, where a simian immunodeficient virus would have been transmitted from non-human primates to humans, thereby becoming one of the now famous sub-types of

27 See Fassin, “Crise épidémiologique et drame social” in Fassin (ed), Afflictions, 9-11.
HIV. The crossing of the barrier between species probably occurred in Central Africa. The circumstances in which this “jump” occurred are purely conjectural but have nevertheless given rise to the most fanciful hypotheses. The phylogenetic analysis of the different variants of the virus leads one to believe that their common ancestor goes back no later than the 1930s. Thanks to tests carried out at a later date on blood samples which had been conserved, it is known that at least one male patient was HIV positive in Leopoldville, present-day Kinshasa, in 1959.

In his study on the reactions to the epidemic in Congo, published in this collection, César Nkuku Khonde reveals the extent to which the idea of an African origin for AIDS was (and still is) inadmissible to that country’s inhabitants, be they literate or not. As Deborah Posel has shown, the vehement refusal of the South African President, Thabo Mbeki, to believe that an African virus could kill so many of the continent’s citizens is made against a background dominated by racist theories concerning the African sexual body which has been common currency since the beginning of colonization. These passions and emotions are as much an historical subject as the theme which has inspired them. No discourse, even though there may be consensus amongst the experts in a discipline, is neutral. Referring to an article in the prestigious American review *Social Science and Medicine*, Gilles Bibeau has shown that some academic research has perpetuated clichés and stereotypes and has “invented” an Africa which exists only in the fantasy world of Western experts. One of the aims of this book is to historicise the academic discourse on AIDS whether one is dealing with the African origin of AIDS or with the discovery, described by Guillaume Lachenal, of atypical serologies in Cameroon.

**Periodisation of AIDS**

In order to be able to think of AIDS historically, one must resort to periodisation. This exercise, it is well known, is as artificial and arbitrary as it is indispensable. Several contributors to this volume have suggested a periodisation. Given the important regional variations, to which I shall return, the most difficult task is to establish a periodisation for the history of AIDS that holds good for the entire African continent. This is what Michel Caraël has tried to do basing his attempt on his experience as a researcher in Rwanda then as a senior member of the WHO Global Programme on AIDS and the United Nations Joint Programme for the Fight against AIDS (UNAIDS).

The periodisation thus proposed refers to the responses by national and international authorities to the AIDS epidemic. Caraël defines three periods: the first which he calls denial

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32 Bibeau, “L’Afrique, terre imaginaire du sida” 126. The Canadian anthropologist refers to J. P. Rushston and A. G. Bogert., « Population differences and Susceptibility to AIDS: an Evolutionary Analysis”, *Social Science and Medicine*, 28/12 (1989), 1211-1220. According to these authors, Africans are genetically and socially programmed to be less sexually inhibited than others, thus making them more susceptible to becoming victims of sexually transmissible diseases.
the second characterized by a belated and vertical global response (1989-1994) and the third, still in operation (1995- ) marked by a broadened reaction at international level. This last period is distinguished by a massive injection of funding from the Global Fund for the fight against AIDS and by the American agency Pepfar as well as by patient access to anti-retroviral treatment which is certainly slow and administered erratically.

This periodisation recalls that suggested by Charles Rosenberg in the article mentioned above. As a social phenomenon, says this medical historian, an epidemic unfolds like a play. AIDS – which he studies in the United States but his remarks can be applied to Africa – is not an exception. The gradual acceptance of the epidemic, whose existence was originally denied by the principal social players, constitutes the theme of the first act. The second act highlights the inconsistent and disorganised efforts of the authorities to conquer the disease. Act three sees the galvanisation of collective action which is better informed and more effective. The fourth and last act – here the analogy with the history of AIDS is no longer pertinent – shows the slow withdrawal of the epidemic. The survivors count their dead and reflect on ways of avoiding a similar catastrophe in the future.

Linked to the way in which the different social agents have attempted to respond to the challenge of the epidemic is the way in which they have interpreted and situated it. This is the aim of a story of the history of AIDS which has yet to be written and for which we provide a few facts in the first part of this introduction. Here, too, it is a matter of periodisation.

Another type of periodisation, apparently more “objective” (if one does not take into account the problems caused by methods used for collecting of data) is that based on figures for HIV prevalence.

In 1989 Grmek could still write that “the United States remains the part of the world most infected [by AIDS]”. The Atlanta CDC reported 86,000 cases at that time, compared to 23,000 cases reported by the WHO in Africa at the same date. For the entire world, the WHO reported 145,000 cases. In fifteen years the situation has considerably changed, as much from the point of view of monitoring methods, henceforth routine in many African countries, as from that of the figures themselves. The most accurate data and the most easily comparable are the levels of HIV prevalence obtained from samples taken from pregnant women at surveillance sites. These are the most commonly used figures even if, it must be mentioned, some analysts dispute their value mainly because of the differences shown in data collected during surveys in homes. Let us recall that in the eyes of UNAIDS and WHO a country or a region is in a state of generalised epidemic when the level of HIV prevalence amongst pregnant women is more than one per cent.

As far as I know, the only author who has suggested a periodisation of AIDS based on official figures for HIV prevalence is Jeanne-Marie Amat-Roze, a French geographer who, in 2002, devoted a thesis to the geography of the HIV/AIDS infection. At the end of the 1980s, she explains, the epidemic was firmly entrenched in the “pioneer” territories of the epidemic (Ivory Coast, Central African Republic, Rwanda, Burundi, Uganda, Tanzania, Zambia, Zimbabwe). Beyond these territories, the virus was more unobtrusive amongst the

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34 Rosenberg, “What is an epidemic?” (see footnote 4).
35 Grmek, Histoire du sida, 316. This remark obviously changes in the third edition of his book (1995) when Africa is presented as “the continent which is the most affected [by AIDS]” (373).
36 Ibid.
37 See Fassin, “Crise épidémiologique et drame social”, in Fassin (ed), Afflictions. 12.
38 Those provided by the WHO and UNAIDS in their annual reports.
general population. The decade of the 1990s saw Southern Africa set on fire. Whilst the number of new cases seemed to reach a ceiling in several regions of Central, East and West Africa, it exploded in the south where unequalled levels were reached. The figures for HIV prevalence continued to mount in Zambia, Zimbabwe and Malawi as if these countries, after having followed the movement of the first decade, were henceforth moved by that of the second.\footnote{Ibid., 125-127.}

In the study which he presents in this volume on the training of health workers in the Eastern Cape in South Africa, Stephen van Houten suggests a third type of periodisation, restricted to a more limited territory and based on the experience of those engaged in the fight against AIDS. This more “subjective” form of periodisation corrects and complements the preceding forms.

In South Africa, as has just been mentioned, the epidemic arrived a decade later than in Central and Eastern Africa, and even later in the Eastern Cape, with KwaZulu-Natal and neighbouring provinces having been the first to show high levels of HIV prevalence. It is not surprising, therefore, that van Houten chose the year 1990 as terminus a quo. The first period, which he dates from 1990-1994, is characterised by a poor knowledge of AIDS on the part of the health workers, slight involvement on the part of governmental and professional bodies in the fight against AIDS and priority given by the NGO sector to awareness campaigns. The second period, the so-called growth of the epidemic period, which stretched from 1995 to 1998, is marked by higher HIV positive figures and hence a greater demand by HIV positive people on associations fighting against AIDS. The third period, that of generalised epidemic, is characterised by a general acceptance by the health workers in training centres, of the gravity of the problem and by the feeling, in the NGO world, of being overtaken by needs.

Such periodisations can be multiplied. Each context calls for its own special one. In her contribution on the Tonga in the Gwembe Valley, Elizabeth Colson shows how AIDS could initially be ignored because of its resemblance to other chronic, already existing, diseases. When – towards 1990 – it became clear that its transmission was of a sexual nature, those affected and their families adopted a position of denial so as to avoid stigmatisation. A new stage began in the last years of the 20th century when the massive growth in the number of AIDS related deaths made denial useless. The advent of retrovirals, to which only the wealthiest have access, in its turn, signalled a new period marked, as noted by Colson, by new moral dilemmas.

The history of AIDS in Africa demands a fine chronology which is based not only on official levels of HIV prevalence but also on the experience of those involved whilst account must be taken of local and regional differences. No less necessary are thematic chronologies. Each category of person involved experiences AIDS according to his/her own periodisation. This book calls to mind the time of the doctor (Kocheleff), that of health workers (Bayer and Oppenheimer), of virologists (Lachenal) and of ethics committees (Becker). Similar studies could be undertaken involving political decision makers, ministers of religion, traditional healers, businessmen and women or teachers.

### Explaining regional variations

Another unresolved question is that of regional variations. Here, too, a combination of biomedical, anthropological and historical approaches allows one to understand better the dynamics of the epidemic.

As the diachronic study of maps charting HIV prevalence illustrates, the spread of AIDS in sub-Saharan Africa is heterogeneous. Three facts clearly appear. The first is the “lateness”
of Southern Africa or, more precisely, the southern most part of Southern Africa (South Africa, Lesotho, Swaziland, Botswana, Namibia). During the 1990s these countries were relatively unscathed. In South Africa where the first two cases of HIV/AIDS were diagnosed in 1982, the level of HIV prevalence in adults was estimated at 0.73% in 1990, the date of the establishment of monitoring sites in the country. In 1995 it had climbed to 10.44% and today is above 20%.  

Originally restricted to white homosexual milieus, the epidemic subsequently affected the entire population with the highest levels being observed in Africans of average socio-economic status living in urban and peri-urban areas.

The second remarkable fact is the heterogeneousness of the epidemiological situation in sub-Saharan Africa. Generally speaking, West Africa is the sub region which is the least affected with, however, peaks in Ivory Coast, Burkina-Faso and Nigeria. In Central and East Africa where the highest levels were shown during the first decade of the epidemic, there has been a relative stabilisation during the past few years, with a level ranging between 5 and 15%. It is in Southern Africa, as we have seen, that the situations is the most catastrophic with Botswana and, recently, Swaziland holding the sad record of the highest HIV level in the world.

To the variations which exist between countries must be added those which affect regions within one country, variations, it must be added, which evolve with time. Rural areas are not necessarily those least affected. In Kenya, for example, it is in Kisumu and not, as one would expect, in Nairobi or Mombassa, the two largest built-up areas in the country, that the highest HIV levels were first observed. The reason is the proximity to Uganda where the epidemic had reached a peak in the middle of the 1980s. In South Africa, KwaZulu-Natal was the most affected province for the most part of the 1990s before being joined by other parts of the country, including the Western Cape which appeared to have been relatively immune initially. Let us end by citing the case of Tanzania, studied by Philip Setel, where, between 1987 and 1993, simultaneous levels of HIV prevalence were given that differed from 10% in the region of Kagera in the extreme west of the country to 2% in the region of Kilimanjaro in the North-East.

The third fact which demands an explanation is the withdrawal of the epidemic in Uganda as well as, it would seem, certain regions bordering on Tanzania. This topic is discussed in the present volume by James Putzel. From 30% in 1992/3 the level of those who are HIV positive in the adult population of Kampala progressively declined to stabilise at 6% in 2004. Putzel also queries the related question of the (relative) non-development of the epidemic in Senegal. In this country, the rate of those who are HIV positive has, in effect, remained at a very low level compared with that of other sub-Saharan African countries.

**The paths of the epidemic**

How can the variations in the spatiotemporal distribution of the epidemic be explained? Recent studies, some of which are included in this book, propose that one distinguish between

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42 Helen Schneider, “Le passé dans le présent”, 89-90.
two types of variables, those linked to exposure to the virus and those linked to its transmission.44

Exposure to the virus depends on the age at which one has one’s first sexual contact, the frequency of sexual contact, the type of sexual contact, the number of sexual partners and, in the case of multi sexual partners, its concomitant or sequential nature. Studies on the history and the anthropology of sexuality, which have multiplied in the past ten years, throw a new light on reasons which encourage Africans to adopt, according to an expression which today seems ambiguous, “at risk behaviour”. Poverty and even more the gap between the rich and the poor greatly influence sexual behaviour as can be seen by the young South African girls who offer their favours to sugar daddies in exchange for food (survival sexuality) or consumer goods (commercial sexuality).45 To this can be added the effects of migration, either internal or external. Yves Zoa, in the article included in this volume, points out the role played by movements of cattle breeders (mainly men) in the spread of the HIV virus in the Lake Chad basin. The sexual behaviour of these men is a reaction to specific reasons. Similarly, a migrant woman, without any social ties, who accepts sharing the bed of a single man so as not to have to sleep in the streets, knows what she is doing, even if she runs the risk of contracting AIDS. The wife of a migrant labourer who engages in sex in different places at the same time is not ignorant of the fact that she could contract the virus but rules of “respect” forbid her asking her husband any questions concerning his sexual activity. We are far from the analyses undertaken during the early stages of the epidemic according to which prostitutes, truck drivers and soldiers were seen as the main carriers of the epidemic. Rather than at “risk behaviour”, an expression which has moral connotations or is paternalistic, the expression “dangerous environments”46 is used.

The study of sexual behaviour in Africa must be undertaken with precaution because of the force of cultural prejudices which often, unconsciously, skew the results. Many writers do not resist the temptation of blaming the African people for the disaster which they are experiencing. An example is found in the study by two Australian demographers, John and Pat Caldwell47 who claim, with no empirical basis, that the high levels of HIV in Africa are due to sexual behaviour on the continent, behaviour which, according to them, is caused by weak marriage ties, the frequency of polygamy, the exclusive role of the mother in the education of children and the refusal by women to indulge in sexual contact after birth. These different features allegedly form a coherent system which, according to the authors, explains the AIDS explosion in Africa.48

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44 My ideas have been prompted by an article by Benoît Ferry (« Systèmes d’échanges sexuels et transmission du VIH/sida », in Becker et al., Vivre et penser le sida en Afrique, p.237-255). See also Mburano Rwenge « Facteurs contextuels de la transmission sexuelle du sida en Afrique subsaharienne : une synthèse », ibid, 217-236. I have avoided the expression “vulnerability” which is often employed in writings on AIDS because of it being too general. In fact it covers two very different realities: physiological vulnerability and social vulnerability. Cf Laurent Vidal, “Anthropologie d’une distance”, 21-23.


Significantly, studies into sexual behaviours which have been undertaken since the beginning of the 1980s in several African countries with high HIV positive levels have not shown significantly different results from those obtained in Western societies or in African countries with low HIV levels.\(^49\) As far as Anne Buvé is concerned, the variations noted between the HIV levels in four African towns are due less to the frequency of so-called at risk behaviours than to factors which influence transmission such as lack of circumcision or the high rate of sexually transmitted diseases. Sexual behaviour certainly plays a role in the transmission of AIDS but in a way which is more complex than initially believed. It is not necessary to postulate intense sexual behaviour in order to explain the rapid transmission of the virus in the urban and peri-urban levels of the populace. It is the general instability which makes sexual behaviours dangerous, an instability which, sometimes for decades, has been nourished by urbanisation, migrant labour and poverty.

Let us now consider the variables linked to the transmission of the virus. There can be no transmission of the virus unless one has been exposed to it. But every sexual act – the most common form of exposure to HIV in sub-Saharan Africa – does not necessarily contaminate, far from it. Certain material circumstances increase, sometimes considerably, the probability of infection.

Firstly, it is advisable to consider those factors which hinder the transmission of the virus. The most well known is the condom. According to sources quoted by James Putzel, the use of the condom has probably contributed to the decline of AIDS in Uganda where the level of use has gone from 16% in 1995 to 40% in 2000. According to Anne Buvé, the good results obtained in Thailand in the fight against AIDS are due, partially at least, to the massive campaigns, launched at the beginning of the epidemic, promoting condoms amongst prostitutes. Conversely, it can be noted that cultural constraints on communication between spouses make the use of condoms difficult, thereby increasing the probability of infection.

There is now-a-days a consensus concerning the negative associations between male circumcision and the transmission of AIDS to which Anne Buvé alludes in her study. Non-circumcision increases the probability of lesions to the foreskin and therefore that of the transmission of the virus.

The same argument, but inverted, holds true for sexually transmitted diseases, sexual violence and dry sex.\(^50\) All practices which cause irritation or lesions to the vaginal wall favour the transmission of the virus. Their spreading can explain high levels of HIV in certain regions. It is incontestable, for example, that the endemic presence of sexually transmitted diseases in the populace, due to the lack of medical infrastructures, has played a major role in the spread of AIDS in sub-Saharan Africa. The high rate of rape in South Africa – more than fifty thousand cases are annually reported to the police\(^51\) – is certainly one of the contributory factors to the high rate of HIV in this country. As for dry sex, the fact that it is extensively practised in KwaZulu-Natal explains, at least partially, why this province is the most affected in South Africa.\(^52\)

Another variable linked to the transmission of HIV is the type of virus. It is known that the second type of virus, HIV-2, which is wide-spread in West Africa, is less virulent than the first, HIV-1 which is found in the rest of the world. However, as Putzel notes with reference to Senegal, HIV-1 tends to impose itself on HIV-2. The two types are not mutually exclusive.


\(^{49}\) Schneider, “Le passé dans le présent”, 87.

\(^{50}\) Insertion of substances into the vagina so as to dry it or to contract it, thereby increasing sexual pleasure.


\(^{52}\) Information kindly supplied by Dr Paul Kocheleff. Regarding Zimbabwe, see Diane Civic and David Wilson, “Dry sex in Zimbabwe and implications for condom use”, Social Science and Medicine, 42/1 (1996), 91-98.
The higher rate of resistance to the virus in West Africa seems to be abating. It has also been noted that HIV-1 has eight or nine sub-types. However, according to Anne Buvé, it has not been proved that differences in the sub-types have had an impact on the spread of AIDS.

The human factor

Let us return to the questions which were raised earlier. Why are certain regions of sub-Saharan Africa more affected by AIDS than others? How can the decline of the disease in countries like Uganda be explained? These questions, which are of interest mainly to those involved in the fight against AIDS, human science experts and particularly historians have answers, albeit partial. In the light of recent work, including that published here, I would like to suggest three avenues of reflection.

The first involves the silence and shame which surround AIDS. The stigmatisation of the disease, a veritable “epidemic within an epidemic” hinders prevention efforts, undermines patients’ moral and physical health and obstruct care and treatment possibilities. As Benedict Carton has demonstrated, the feeling of shame which accompanies AIDS has its roots in history and culture. Only an in-depth study of the way in which traditional societies and their colonial archetypes have experienced sexual behaviour, disease and death will allow one to understand why, twenty years after the beginning of the epidemic, AIDS continues to be indefinable and, to paraphrase Didier Fassin, unbelievable.

Secondly, in order to be fruitful, this critical work must include some reflection on the knowledgeable or pseudo-knowledgeable discourse on AIDS. Studies such as those by Charles Becker on the history of ethics and law in Senegal or by Guillaume Lachenal on the methodologies of European researchers in Cameroon are indispensable. The language of medical doctors, researchers, international experts, journalists and literary writers needs to be understood as much as does that of the sick and their families. From this aspect, the work undertaken by Ronald Bayer and Gerald Oppenheimer amongst a group of South African doctors is priceless.

Finally, the case of Uganda suggests a reflection on the role of politicians and religion figures in the fight against AIDS. The preceding paragraphs have alluded to social and cultural determinisms which affect the evolution of the epidemic. Are we condemned to impotence? Is our only hope that of seeing the AIDS growth curve level out, as has been the case in several Central and Western African countries, because of a phenomenon of “natural” saturation with the number of new cases of infection being equivalent to that of those who have died? The Ugandan example illustrates, by contrast, the positive role which the State can play if there is synergy with religious groups and NGOs. Methods exists for slowing down the progress of the epidemic, first of which is the use of condoms, assuming responsibility for sexually transmissible diseases and therapy using antiretrovirals. But in order for these means to be implemented, a medical and social infrastructure is necessary. This is where the State has a role to play. In Senegal, for example, the fact that infrastructures set in place during the colonial period have been maintained after independence, meant that a relatively effective policy of prevention and treatment could be adopted at the outset of the epidemic. A contrario, the critical attitude adopted by the Burundian government during the 1980s and the procrastinations of the South African government in the following decade have contributed, as Paul Kocheleff has shown, to the lack of success of preventative policies in these two


54 Fassin, “L’inclusion de l’inégalité”, 27.
countries. The lack of cooperation in prevention of AIDS programmes on the part of religious authorities in Burundi also explains, according to him, the rapid spread of the epidemic in this country.

Let us not, however, make a scapegoat of political and religious authorities. AIDS is a disease which concerns the entire society and not only those in power. The South African example shows how, in this area as in many others, the present depends on the past. It is incumbent upon historians and specialists in human sciences to explain how the epidemic becomes entrenched in the society which it affects. This will be their contribution to the fight against AIDS.

*(translated from the French by Carole Beckett)*
Part Two

The Dynamic of the Epidemic
Twentieth Years of Intervention and Controversy

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1. Preamble

The story of AIDS can be written in hundreds of ways. Depending on whether one has lived with it in Lusaka or in Brussels, whether it is seen from a clinical point of view, from a demographic or even from a social point of view, from the viewpoint of someone who is infected with the disease, or from that of a mere observer. History is always a viewpoint and varies according to the way you perceive the world around you and your ability to place yourself within, as Fabrice del Dongo helplessly commented, at Waterloo. And it would be presumptuous to speak of it here without care. The periodisation proposed in this article describing reactions to the HIV epidemic covers three phases over a twenty year time span: this period needs to be seen as provisional, within the scope of contemporary history.

The remarks which follow are those of a player at international level, involved as a researcher from 1983 in several AIDS studies in Rwanda, then, from 1987, under the aegis of the World AIDS programme sponsored by the World Health Organization (WHO). When, ten years later, in 1996, the joint United Nations programme for the fight against AIDS (UNAIDS) began its activities, the author coordinated the programmes concerning prevention, research and evaluation, until relatively recently.

The story of an epidemic unfolds at several interwoven levels, local, national and international at the same time, following the rhythm of research progress, the ups and downs of international financing, the mobilization of activists from New York to Johannesburg. HIV is a modern phenomenon: it could only have multiplied in the twentieth century, a time when urbanization, mobility, migrations and international travel have all transformed the world into a vast connected network which has allowed a virus ensconced in the blood of a few people to contaminate more than 70 million in less than forty years.

2. Emergence of a new syndrome

The construction of the acquired immunodeficient syndrome (AIDS) came about gradually. The first clinical symptoms were initially described in June 1981 in Los Angeles, United States, in five men who had a rare form of pneumonia caused by a protozoon *Pneumocystis carinii*, with no known risk factors.¹ The new syndrome was seen as an ailment affecting only “marginal” and “deviant” groups described in the press by the term the 4H: homosexuals, heroin addicts, (intravenous drug addicts), hemophiliacs and Haitians. For several months, the latter group was suspected of having imported the epidemic into the United States. But from 1984-85 the virus responsible for the new syndrome was identified: the first tests which

enabled the identification of “healthy” carriers were developed; the main methods of transmission were described: sexual contact, blood and mother to child transmission.

Today it is difficult to recall the overwhelming fear of the 1984-86 period faced with the sudden scale of an epidemic which seemed to spread invisibly. In the United States, in a few months, thanks to tests, eight thousand infected people were identified in forty-four states and thousands in northern and southern Europe. All the continents registered their first cases; soon all countries did the same. The press looked for historical precedents and, inevitably, comparisons with epidemics of the plague in Europe caused the fears and need for protection of bygone ages to reappear. This reaction of panic amongst the general public can be explained by the discovery of carriers of the virus who had no obvious symptoms, by the uncertainty at the time of ways of transmission such as saliva or simple physical contact, by the fatal nature of AIDS and the powerlessness of medicine. Fundamentally, it was a reaction to the symbolism attached to the transmission of the disease: sex and blood, touchstone of all fears. Fear lead to the social rejection of those who were affected, homophobia ensued and groups with at-risk behaviour were pilloried. Stigmatization and the rejection of infected people were made in the name of morals, religion and also race.

An “African” AIDS?

The awareness of the existence of AIDS in sub-Saharan Africa arose from 1983 with the description of several cases amongst African patients who had been hospitalized in Belgium and France. A few months later, the syndrome was described in the hospitals in Kigali, Rwanda and Kinshasa, Zaire; then in Uganda under the name slim disease.

Tests, which were later carried out on stored blood, confirmed the presence of the virus in central Africa from the end of the 1950s, both in rural and urban areas. But it is likely that the epidemic of the infectious AIDS virus, the human immunodeficient virus HIV, began towards the middle or end of the 1970s and then slowly spread through several continents amongst the most vulnerable populations.

When the epidemic was identified in Africa, the prevalence of HIV amongst the urban population in several central African capital cities was already high: in 1988 in Kigali 30% of the adults were infected; 60-80% of the prostitutes in Butare, the second city in Rwanda and similar proportions of infection were seen amongst the prostitutes in Bujumbura, Lusaka and Nairobi. The epidemic appeared to be mild in rural milieux except for the districts in the south of Uganda where the Tanzanian army had been stationed during the war against Amin Dada’s regime.

In spite of the high level of the infection in urban areas in central Africa, the visibility of the epidemic remained extremely low. Many infected adult patients died in hospitals or at home from opportunistic diseases, such as diarrhea or tuberculosis, associated with the virus. Overworked clinicians who did not have access to blood tests, were not inclined to disclose to the patients or to his/her family a diagnosis of a disease associated with sexual promiscuity.

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During several stays in Uganda in 1984 and 1985 in the rural district of Masaka, I visited several villages where young adults were dying in fear and destitution. The villagers questioned themselves as to the origin of this new scourge which they associated with the upheavals provoked by civil war. They had already seen, by observing the families who were affected by the disease, that the infection was transmitted through heterosexual channels, sometimes from mother to child and not through simple contact.

The scientific world had not yet accepted the idea that HIV was transmitted heterosexually. The transmission of the virus from man to woman was recognized but not that of woman to man. In fact, in high income countries homosexuals represented the large majority of sick people who had been infected through sexual contact, and in the case of intravenous drug addicts who share syringes the majority are male. For many years, scientific evidence had to be collected and the dominating role played by other sexually transmitted diseases in the speeding-up of the transmission of the virus had to be demonstrated before the transmission of the disease from woman to man was accepted and a stop put to the idea of an African AIDS, an idea associated with sub-Saharan Africa.

In fact, a debate had begun concerning the origin of this new virus – new viruses because HIV-2 had been discovered – and its genetic similarities with SIV in central African monkeys. This scientific debate which was important for the future development of a vaccine, immediately caused northern countries to develop racial attitudes towards Africans and to offend the African intellectual elite. Threats to freedom were obvious: sections of public opinion demanded control measures at border posts for those who were HIV positive, compulsory tests for at risk groups and the isolation of those who had AIDS. Stigmatism was at a very high level.


The reactions of African governments to the HIV epidemic were shaped by this international context. The refusal to recognize the existence and the extent of the epidemic was demonstrated by both the authorities and the African elites including the great majority of the medical fraternity. AIDS became a political and cultural stake before being a health problem. Reactions of nationalistic pride were exacerbated by the debate on the African origin of the virus or on “African sexual promiscuity”. The African elites denounced AIDS as a foreign disease spread on the continent by white homosexuals, as an attempt to bring down the birth rate by imposing the use of condoms, as an attack associated with the puritanism of Christian sects in the face of African traditions such as polygamy.

Wait-and-see governments

The majority of sub-Saharan African governments, with a few exceptions such as Uganda, Zaire, Zambia and Senegal, denied the reality of the epidemic for a long time or demonstrated a cynical scepticism, accepting international aid without really combating the virus. The infection which was associated in rich countries with homosexual behaviour, prostitution or intravenous drug usage seemed impossible in Africa. When local studies showed that the level of HIV infection was particularly high amongst blood donors, prostitutes, patients with STDs the majority of governments denounced the insults made to African culture, to their countries’ reputation and their economy which often partially depended on tourism.

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Confronted with epidemiological facts which were more and more troubling, but often abstract and difficult to understand, the authorities denial took on several different forms: the refusal to accept the existence of a new syndrome; a policy of secrecy concerning the number of infections; accusations against the research teams most of which were foreign and unfamiliar with communication policies; denunciation of blood tests which were seen to be unreliable; suspicion concerning therapeutic procedures; promotion of miracle cures inspired by local research. This negative conformism in the face of an increasing number of sick and dying as well as the extraordinary passivity of Ministries of Health can be explained by the fact that the political and medical systems are cut off from the rest of society.

**Societies in search of an answer to the new syndrome**

Amongst the local people, scepticism and disbelief in the face of a local epidemic had long been a characteristic of its presence. AIDS was seen as the distinctive disease of the Other, linked to foreigners: Whites, prostitutes, truck drivers, migrants and towns folk. The death rate due to AIDS was hidden by both doctors and family members which made the public awareness of the disease difficult. For these reasons, there were no specific demands or public pressure on the State or on health services.¹

Where the mortality rate was high as a result of AIDS, the disease was diagnosed in the light of local beliefs and linked to other diseases like tuberculoses. In many ethnic African cultures, a fatal disease is never “natural” even if it has been brought on by a virus. Chronic illness or premature death are the penalties for having disobeyed prohibitions. In other cultures, witchcraft and malevolent acts explain premature adult death. In both cases, individual prevention is not of importance. “Messages” on faithfulness or the use of condoms remained formal and exterior to the culture: they were not assimilated at the level of sexual behaviour.²

Sexuality is the domain *par excellence* of rules and regulations, the prime area where nature and nurture are linked. It belongs to the world of impurity and filth. It is dangerous, an inexhaustible source of individual and social problems. Communication about sexuality is highly codified. Contrary to popular belief, sexuality is rarely spoken about in African society: even President Mandela, the best ambassador for the fight against AIDS, has never openly confronted it in his public addresses in South Africa.

The doctrine of predestination is also widely spread: it is the religious expression of the fact that in a world of rarity, success and failure, health and sickness, life and death are not dependant upon clever or preventative behaviour but on circumstances beyond individual control: “fate” is fashioned by higher powers, some known, others unknown.

Because of their diversity, all these factors specific to the African continent have undeniably contributed to slowing down changes in individual behaviour and to rigidifying consciences. They have also encouraged the isolation of the ill and the absence of communal reactions.


The WHO, the international organization in charge of epidemics, reacted belatedly as the result of an historic error in judgment on the part of Dr Halfdan T Mahler, director general at the time, who admitted to not having recognized the epidemic and universal character of the syndrome before 1986.

Then, very rapidly, in 1987, with the creation of the Global Programme for the Fight against AIDS (GPA, Global Programme on AIDS) modeled on the fight against smallpox, national programmes to fight against AIDS were set up and funds allocated to ministries of health. Priority was given to the African continent. By the end of 1989 in an effort without precedent, 160 countries had established, often in great haste, the basis of national programmes of struggle. At the end of the year, for the very first time, an international summit devoted entirely to AIDS brought ministers of health together in London.

The philosophy behind the global programme and the conceptual framework of the battle against the epidemic defined by Jonathan Mann, the first director of GPA, was based on a few general principles: “Public health must be protected, the rights of man must be respected” and “education is the key to the prevention of AIDS; the transmission of HIV can be prevented by informed and responsible behaviour.” The WHO had set up a strategy to fight against AIDS which can briefly be summarized as follows:

– Priority to be given to the threatened rights of infected persons in a context where coercion, compulsory tests and means of isolating the sick were multiplying. The main effect of these prohibitionary policies was to drive at-risk people or groups underground, far from access to information and services, and to considerably limit preventative efforts.

– Stress on the all-important role of information, education, communication and the control of the sexual transmission of HIV by simple methods to reduce the risks: delay first sexual relations, limit the number of partners, develop a means of controlling STDs and the use of condoms.

– A rational model of protection against the infection, based on individual responsibility, which presupposes that those who are informed of the dangers of transmission of the virus would choose a life style that would protect them from the virus.

– A psycho-medical perception of social conditions which reflects a humanistic but simplified vision of real societies.

Successes in the North

Public health authorities in high-income countries have stressed information, means of transmission of the virus and means of protection and services. With differing success rates, politically organized groups such as homosexuals in the United States, Australia and Western Europe have managed to obtain some access to financial resources and have organized programmes with specific aims. Partnerships between health personnel, NGOs, and people infected or living with AIDS created a new militancy, fostered a political and media approach and maintained pressure on public authorities. Sex education was introduced into secondary schools and the use of condoms from the earliest sexual contact become widespread. The epidemic slowed down in rich countries, not only amongst homosexuals but also amongst intravenous drug addicts once it had been proved that sharing needles was dangerous.

However, the example of Eastern Europe reminded the world that social changes and socio-economic upheavals played an even more important role in the evolution of HIV epidemics than individual efforts of prevention. Whilst for more than ten years the HIV epidemic had remained constant at an extremely low level in the USSR, the fall of the wall

and the collapse of the system of values in the former Soviet Union brought about a rapid growth in the use of intravenous drugs and prostitution and a surge of HIV infection.1

A developmental crises context in sub-Saharan Africa

Cultural and historical contexts view epidemics as having different dynamics and national responses must adapt themselves in order to be effective. The HIV epidemic in Africa appeared in a context of crisis for development models: increased socio-economic inequalities, chaotic urbanization, crises in rural areas, deterioration of exchange rates, increased external debt in twenty two countries out of forty-four. From the beginning of the 1980s, sub-Saharan Africa experienced a regression in all the developmental indices with the lowest socio-economic parameters in the world (levels of literacy, of schooling, infant mortality, life expectancy) and the most unfavourable level of social security cover (doctor/patient ratio, access to health services). Eighteen out of nineteen worldwide famines between 1975 and 1990 were African. Since the 1980s more than half of the African countries have experienced conflicts. The number of refugees and displaced persons was estimated at close to ten million. These crises and this structural deterioration were due to a persistent neo-colonial heritage and “bad governance” tainted with corruption. The programmes of structural adjustment that were set up to “purge” the economies often had devastating effects on the so called “non productive” social sectors such as education, health and social infrastructures.

Fragmented medical strategies for the struggle

The establishment of national strategies to fight against AIDS was strongly influenced by this structural context where little attention was paid to public health and where the HIV epidemic was not seen as a priority. The major weaknesses in national reactions to the epidemic during this period can be pinpointed by a critical retrospective look-back:

- Direct intervention from technical advisors and foreign experts and taking charge of the battle by the WHO contributed in many cases to a national abrogation of responsibility which was facilitated by the low level of political involvement: president, government, parliament, local leaders without the odd civil or community organization taking over.

- Established under the guidance of the Ministries of Health, the national programmes to fight against AIDS inherited all the historical shortcomings of the health sector: weak budgets, rundown infrastructures, lack of personnel, concentration in urban areas, few primary care health facilities, partitioning of care, small projects, lack of priorities, stress on laboratories and individual care etc.

- The absence of a visible impact by AIDS in terms of mortality contributed to the epidemic being interpreted in terms of individual cases which were the concern of the Ministry of Health and the medical corps. The programmes against HIV/AIDS were seen as separate, vertical programmes with their own structures: the other sectors of the government did not feel involved.

- The model for intervention was based on the experience of the fight against other infectious diseases such as smallpox and diarrhea and stressed information, making condoms available and care.

- The conceptual framework – aimed at general and individual information – considerably underestimated the silence and prohibitions regarding sex. Education

retained a medical slant and did not count real experiences such as paid sex, informal sexual relations, multi partners, actual use of condoms etc.

- Financial resources – external for the most part – aimed at medical and governmental prevention were not sufficient for an epidemic in full flood. In many countries, these resources were not used other than in laboratories and blood banks. They gradually dried up when it became clear that the epidemic in the North remained restricted and that the expenditure far outstripped the results obtained.

**Expanding HIV epidemics**

During this time, the epidemic in sub-Saharan Africa continued to spread especially in the east and in the south, as much in urban areas as in rural milieus (figure 1). In 1986, with the exception of a pocket with high levels in the centre of Africa, the national levels of HIV were not, on average, higher than 5%. In 1991, ten countries had levels higher than 10%.

The phenomenon is global. In 1995, the WHO estimated that twenty-four million adults had been infected since the beginning of the epidemic, of whom sixteen million were in Africa. At least five million had died. From then on, AIDS has been the major cause of death amongst adults in cities in the USA, Europe and Africa.¹

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The Ugandan example\textsuperscript{1} and the different dynamics of the epidemic across continents have contributed to international recognition that there are different situations of vulnerability at regional and international level, and from one town to another. The failure of the majority of governmental responses to control the infection marks the end of a unique global strategic model linked to Ministries of Health and centered on individuals.

Moving from a model of psycho-social behaviour modification to a model of at-risk situations involves a paradigm change. The individual risk factors can explain who in the community is infected by the virus but not why this community has a higher level of HIV prevalence than others. Explaining why this is so requires an understanding of the cultural, social and economic factors of the epidemic at local level such as the relationship between men and women, the sexual practices, mobility, the presence of social and health services, participation in community activities and many other factors.\textsuperscript{2} Economic precariousness and the absence of social support are factors that increase vulnerability at local level by limiting the individual’s choice. Henceforth, any action at local level would involve the recognition of the critical role played by communities and associations in modifying the norms and behaviour such as commercialised sexual relationships.

The impact of AIDS on social, cultural and economic development became obvious. The fight against AIDS became a national priority in the countries which were the most affected; it had to concern itself with prevention as much as treatment or social support for affected communities and include all sectors of the community. It required that AIDS be seen as an obstacle to development and as a social and economic handicap and not only an illness.

\textbf{A broader response at global level (1995 to the present day)}

It would have taken a long time to institute strategies and programmes of intervention against what one would call second generation HIV which were based on a broadened and multi-sector framework where governmental pleas would play an important role. At a global level, these changes took place in December 1995 when the WHO coordinated the struggle against AIDS and enforced the creation of a joint secretariat – UNAIDS – with five (shortly ten) United Nation agencies and the World Bank who were, in the future, supposed to unite their efforts in their respective fields so as to broaden the fight against AIDS at both a national and international level. It would take UNAIDS several years to convince the agencies and to impose a common strategy and a consistent sharing of responsibilities on them and it was only towards the end of the 1990s that this vision shared at central level began to be applied by the UN agencies at the level of different countries. The culture of competition and autonomy between agencies gradually made way for a plan of integrated work to support national action against the epidemic.

At the beginning of the 2000s, these changes in global planning and strategy were reflected at national level with the creation of national committees for the fight against AIDS (CNLS) controlled by the countries’ highest authorities which replaced the old structures in the Ministries of Health. These committees consisted of representatives from the main ministries such as education, population planning and youth who were involved in the fight against AIDS as well as representatives from the private sector and civil society. The UN agencies and the main donors at local level were charged with coordinating their support with


the work of the CNLS within thematic groupings. Henceforth, stress was put on integration and on national coverage of programmes of prevention, counseling and health in order to rival the many micro-projects which were operating in isolation in some urban centres.

After a long period of indifference on the part of political and public opinion decision makers, the international community again mobilized itself at the highest level, spurred on by UNAIDS. From now on, AIDS would be discussed in meetings of ministers of finance, the G8, at the Davos forum as much as in those meetings where cancellation of the third world’s debt, developmental crisis and security were discussed. In 2001, almost twenty years after its identification, the 189 member countries of the United Nations eventually devoted an extraordinary General Assembly to AIDS and undertook to implement an impressive series of measures to reduce the level of HIV in their respective countries between 2005 and 2010.

In rich countries, AIDS sufferers’ generalized access to antiretroviral therapies (ART) resulted in a considerable reduction of the mortality rate brought about by the disease. Henceforth, in spite of the cumbersomeness of the treatment and resistance to ART, it became possible to live with AIDS. This clinical progress heightened the awareness of the differences in low revenue countries and particularly Africa where the majority of infected people lived. Differences that were due not so much to public health considerations as to the moral and ethical response to the scandal of the millions of publicised deaths amongst infected people.

The creation of a global fund to fight against malaria, tuberculosis and AIDS was a response to these demands. In 2004 a battle which had been going on for three years about the price of antiretrovirals and the conditions for fixing the prices resulted in a theoretic possibility of countries acquiring tritherapy at a price of US$150-200 per person per annum compared to the $1200 in 1998. Access to medications became possible in the South. The WHO began a “three by five” initiative so that three million AIDS sufferers could benefit from ART by the end of 2005.

**Increased financial resources**

At the same time mobilization for increasing financial resources for the prevention, treatment and social support began to bear fruit in spite of fears which had been expressed at the birth of UNAIDS.\(^1\) Close on five billion dollars had been spent in 2003, half of what was needed to meet needs.\(^2\) This increase in funding came about as a result of bi-lateral aid from rich countries, the increase in contributions of United Nations organizations as well as from national budgets. The total amount still represented only half of what was estimated to be necessary to develop effective programmes but it did allow for the launching of programmes on a national scale including the improvement of services and treatments.

**Provisionary assessment**

The political involvement of African presidents and governments has only recently been asserted, with a few exceptions. National committees for the fight against AIDS – a new institutional creation – have taken the coordination of the fight away from the Ministry of Health. In future, apart from inter-ministerial committees, representatives from civil society and the private sector would be associated. The plan is to extend the programmes on a national scale and to decentralize to district level. It is still too early to judge of the success of

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this broadened strategy and to gauge national responses. In some African countries such as Kenya, Rwanda, Ethiopia and Malawi surveillance of HIV has shown that there is some stabilization of the epidemic but this would appear to be more of a “natural” stabilization linked to the balance between deaths and new cases than growing success of the prevention programmes linked to a broadened conception. However, it is difficult to separate the two effects.

The conditions of a more effective fight on a national scale seem concerted but many weak points and uncertainties remain:

- Community involvement in prevention remains superficial although it appears that in the few countries where there has been country-wide success, this involvement has been absolutely necessary. Stigmatisation amongst the infected remains high. Many attempts at controlled educational programmes in Uganda, Tanzania and Zimbabwe have recently concluded that prevention programmes have hardly been effective although they were multi-faceted and included improvement of services, peer education, gender spread, entrenchment in local organisations. The reasons which have been given to explain these results are often the norms and prohibitions linked to sexual cultures, the lack of community involvement and fears associated with stigmatization.

- Could the expanded response which aimed at attacking the roots of the epidemic by diminishing the structural factors of vulnerability to HIV be translated into programmes which would lead to behavioural changes in matters of sexuality? In order to reduce the vulnerability of young girls to HIV it would be necessary to improve their level of education. But would this not bring about a risk reduction for young girls in a context of general poverty and of competition for a decent social status? Investment in the fight against poverty, the cancellation of debt in the poorest countries, inequalities between men and women and social capital seem necessary and justified for the control of the epidemic but, at the same time, the effects of globalization seem to create more disparities, to destroy local cultures and to reinforce inequalities. The growing exposure in the media and the new life styles which this encouraged, accelerated the break-down in traditional social norms which had limited sexual contact. The new context of possible access to treatment – still far in the future for the majority of African countries – could revitalize the prevention programmes but could also remedicalise the programmes and put a curb on the dynamism of the various associations, as has clearly happened in the rich countries were new infections are increasingly spreading. Many questions remain.

- The most effective prevention strategies for avoiding infections has been evaluated and are widely known. However, at political, moral and religious levels they met with unbelievable resistance. Whether it is a question of risk reduction amongst intravenous drug addicts who share needles, the promotion of the use of condoms amongst prostitutes or preventative services for homosexuals, sex education at schools, innumerable obstacles prevent these strategies from being applied on a large scale and of having an impact on the population. The Bush administration which contributes generously to the fight against AIDS in Africa refuses to finance national programs for youth that would go beyond promoting sexual abstinence.

Over and above this chaotic research to find a combination of means to fight

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against the epidemic, history will remember, apart from the terrible human suffering, the enormous demographic wound occasioned by AIDS with its procession of deaths, which has seen 15 years cut off life expectancy in those countries which are the most affected (figure 2). The demographic effects of this unparalleled mortality rate will be felt up to and beyond 2020 whatever future successes there might be. The extreme case of Botswana (figure 3) where the national level of HIV has reached 37% illustrates the drop in birth rates and the high level of death amongst adults.

History will also recall the curbs on development which have been brought about by the epidemic and, more generally, the inability of societies to organize themselves collectively by showing solidarity in controlling the spread of a sexually transmitted virus which, in a twenty year period, will have affected several scores of millions of people.

For those African countries where the HIV level is high, the story has barely begun. With eleven million orphans in 2003 and twenty million expected by 2010, an entire generation deprived of parents must face the future. This story has yet to be told.

*(translated from the French by Carole Beckett)*
Figure 2: Life expectancy and HIV seroprevalence in six countries from sub-Saharan Africa, 1950-2005

Figure 3: Projected population structure in Botswana in 2020, with and without AIDS mortality

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Introduction

UNAIDS and WHO estimated that there were globally 34 to 46 million people living with HIV by the end of the year 2003. Of these more than 50% (25 to 28.2 million) were living in sub-Saharan Africa which houses about 10% of the world’s population. It is estimated that 7.5 to 8.5% of adults in sub-Saharan Africa are infected with HIV. Africa south of the Sahara is the region in the world worst affected by HIV/AIDS.

UNAIDS and WHO define an HIV epidemic as generalised when the prevalence of HIV infection in pregnant women, used as a proxy for the prevalence in the general adult population, exceeds 1%. Using this definition 33 of the 44 countries in sub-Saharan Africa had a generalised epidemic at the end of 2001. In four countries (Madagascar, Mauritius, Somalia and Senegal) the HIV prevalence in pregnant women was 1% or less. For seven countries, including the Comoros, Djibouti, Gabon, Guinea, Liberia, Mauritania and Niger, no reliable data were available. In the countries with generalised epidemics the HIV prevalence in the adult population ranged between 1.6% in the Gambia and 38.8% in Botswana. In general the populations of Eastern and Southern Africa are more severely affected than the populations of West and Central Africa. In seven countries of Africa, including Botswana, Lesotho, Namibia, South Africa, Swaziland, Zambia and Zimbabwe, at least one in five adults is infected with HIV and all of these countries are in Southern Africa.

There is evidence that differences in prevalence of HIV between different regions in sub-Saharan Africa can not always be explained by differences in time since introduction of the virus into the population. In fact, in most instances, differences in prevalence are the result of differences in rate of spread of HIV in the population. This is illustrated in Table 1 and figure 1 which show trends in HIV prevalence in several African cities. There are striking contrasts in the evolution of the HIV prevalence between Kinshasa (Democratic Republic of Congo) and Yaoundé (Cameroon) on the one hand and Gauteng Province (South Africa) and Gaborone (Botswana) on the other hand. Only the epidemics in Southern Africa can be called explosive.

This paper gives an overview of the evolution of the HIV epidemic in sub-Saharan Africa and reasons will be explored for the heterogeneity of the epidemic in different African regions HIV epidemics. In addition an explanation will be proposed for the severity of the HIV epidemics in sub-Saharan Africa compared to other regions in the world and their severity. This will be done from an epidemiological perspective which means that the focus of the attention will be on behaviours and on biological factors that may explain the course of the HIV epidemics in sub-Saharan Africa.

2. The early years of the HIV epidemics

The acquired immune deficiency syndrome (AIDS) was first described in 1981 in homosexual men in North America, following reports to the Centers for Disease Control on Kaposi’s sarcoma and *Pneumocystis carinii* pneumonia.\(^1\) Cases dating from 1978 and 1979 were retrospectively diagnosed, later on.\(^2\) The first case of AIDS in a Haitian immigrant in the United States was diagnosed in 1980 and up till 1983 AIDS was only described in homosexual men, intravenous drug users (IVDU), haemophiliacs and Haitian immigrants in the United States.\(^3\) The first report on AIDS in patients from Central Africa was published in 1983. The patients, three of whom had been living in Belgium for less than three years, were admitted to hospital in Brussels.\(^4\) This report was followed by investigations in Central Africa\(^5\) and by 1986 it was clear that the human immunodeficiency virus (HIV) had spread in the populations of numerous countries in sub-Saharan Africa and posed a major public health problem there.\(^6\)

In retrospect the first cases of AIDS seem to have appeared in Uganda and Tanzania shortly after the liberation war in Uganda in 1978-1979.\(^7\) The start of the AIDS epidemic in the Democratic Republic of Congo is situated around the same time,\(^8\) although HIV infection may have been present in the population many years before that time. Antibodies against HIV were detected in a serum sample collected from a Kinshasa resident in 1959.\(^9\)

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\(^{3}\) Ibid.


Table 1  
Trends in HIV seroprevalence among pregnant women in selected capital cities in sub-Saharan Africa

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There have been heated discussions about the origins of HIV but unfortunately not all these discussions were based on sound scientific evidence. Nowdays there is a consensus among virologists that HIV in humans is a zoonosis, i.e. that simian immunodeficiency viruses have been transmitted from non-human primates to humans. Five lines of evidence are used to substantiate cross-species transmission: similarities in viral genome organization, phylogenetic relatedness, occurrence of SIV in the host population, geographical coincidence, and plausible routes of transmission.⁵ HIV-2 and SIV in sooty mangabeys in West Africa were the first viruses for which these criteria were satisfied. Finding the origins of HIV-1 proved more difficult but current evidence suggests that it originated from SIV in chimpanzees in West Central Africa.⁶ Exposure of humans to blood and tissues of infected primates during hunting and butchering is thought to be the most plausible route for these cross-species transmissions. Phylogenetic analysis of different HIV-1 strains dates the presence of the common ancestor of the different strains in the human population as far back as 1931.⁷ What may have happened in the time between the first introductions of SIV/HIV in the human population and the appearance of increasing numbers of patients with AIDS in the early 1980's remains uncertain. Work with mathematical models however offers a plausible

¹The data in the tables are for HIV-1.
²Until 1990 the date for Mama Yemo Hospital, the largest maternity clinic in town. The prevalence figure of 1992 is also from Mama Yemo Hospital.
³Nigeria.
⁴Data from 1992 on are for one for the four sentinel sites in Lusaka (Zambia) where intermediate HIV prevalence rates are found.
⁶Ibid.
explanation why HIV infection may have remained unnoticed for many decades. Because of the nature of the zoonotic transmission, the first HIV infections would have occurred in isolated populations with limited sexual networks outside the village. These first HIV infections affected only limited numbers of people and as such could not spark off an epidemic. However increased population growth rates and migration would have created the conditions for a more extensive spread of HIV.

3. The spread of HIV in sub-Saharan Africa

Reconstructing the spread of HIV infection in sub-Saharan Africa is fraught with many difficulties. When trying to get a picture of the early years of the HIV epidemic we are faced with the problem that no reliable diagnostic test existed until 1985 when the first antibody test for the detection of HIV infection was approved by the United States Food and Drug Administration. Up till the mid 1980s we have to rely on clinical reports and (few) stored serum samples.

Table 2  Historical development of the HIV epidemic in sub-Saharan Africa

<table>
<thead>
<tr>
<th>Year</th>
<th>Sub-Saharan Africa</th>
<th>World</th>
</tr>
</thead>
<tbody>
<tr>
<td>1930s (?)</td>
<td>Simian immunodeficiency viruses are transmitted from non-human primates to humans.</td>
<td></td>
</tr>
<tr>
<td>1959</td>
<td>A serum sample is collected from a Kinshasa resident with HIV infection, and stored to be tested more than 20 years later.</td>
<td></td>
</tr>
<tr>
<td>1980</td>
<td>Increasing numbers of patients with a new syndrome, “Slim Disease”, are reported by doctors in Uganda and Tanzania. Later Slim Disease was found to be AIDS.</td>
<td></td>
</tr>
<tr>
<td>1981</td>
<td>The first cases of AIDS are described in gay men in the United States.</td>
<td></td>
</tr>
<tr>
<td>1983</td>
<td>Patients from sub-Saharan who are admitted to hospital in Brussels are diagnosed with AIDS. They do not have any of the known risk factors for AIDS and provide the first evidence that AIDS is transmitted through heterosexual intercourse.</td>
<td>The human immunodeficiency virus is identified as the cause of AIDS.</td>
</tr>
<tr>
<td>1984</td>
<td>According to estimates by WHO 1 to 5% of adults in 11 African countries are infected with HIV. These countries are Uganda, Rwanda, Burundi, Tanzania, Zambia, Zimbabwe, Ivory Coast, Burkina Faso, Togo, Cameroon and Congo Brazzaville.</td>
<td></td>
</tr>
<tr>
<td>1985</td>
<td>According to estimates by WHO more than 10% of adults in Zambia and Zimbabwe are HIV infected. Zambia and Zimbabwe are the countries with the highest HIV rates in the world.2</td>
<td>The first antibody test to detect HIV infection is approved by the FDA of the United States of America. At least one case of HIV/AIDS has been reported from every region in the world.</td>
</tr>
<tr>
<td>1989</td>
<td>According to estimates by WHO more than 10% of adults in Zambia and Zimbabwe are HIV infected. Zambia and Zimbabwe are the countries with the highest HIV rates in the world.2</td>
<td></td>
</tr>
<tr>
<td>1991-1993</td>
<td>HIV prevalence in young pregnant women in Uganda begins to decrease, the first major decrease in HIV prevalence in a developing country.</td>
<td>An HIV outbreak in Eastern Europe is recorded in intravenous drug users.</td>
</tr>
<tr>
<td>1994</td>
<td>The HIV epidemic has shifted to Southern Africa, including South Africa.</td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>The majority of countries in sub-Saharan Africa have a generalised HIV epidemic.</td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>Globally an estimated 34 to 46 million people are living with HIV/AIDS.</td>
<td></td>
</tr>
</tbody>
</table>

Tracking the spread of HIV infection in a population, however, is not only conditional on the availability of reliable diagnostic tests but also on a well functioning surveillance system that provides estimates of HIV infection in representative samples of the general population and special vulnerable sub-populations. Because of the stigma attached to HIV/AIDS there were considerable delays in most African countries in facing up to the problem and setting up systems to collect high quality data on the spread of the infection. With these caveats in mind the table below is an attempt to describe the historical development of the HIV epidemics in sub-Saharan Africa and in the world.

4. The predominant mode of transmission of HIV in Africa: sex or injections?

When AIDS was first described in African patients who were neither homosexual men nor intravenous drug users, epidemiologists realised that HIV could also be transmitted through heterosexual intercourse. Since the early years of the HIV epidemics in sub-Saharan Africa it has been estimated that over 90% of HIV infections in adults are acquired through heterosexual intercourse. Recently WHO has estimated that only 2.5% of all HIV infections in sub-Saharan Africa are due to inadequate sterilisation of skin piercing instruments. This low estimate of the proportion of HIV infections in sub-Saharan Africa attributable to injections has been challenged. Gisselquist and his colleagues argued that heterosexual transmission could not explain the high rates of HIV infection found in Africa and they estimated that 20 to 40% of HIV infections on the continent are in fact due to unsafe injections in health care settings. However their arguments and estimates could not withstand the test of closer scrutiny for a variety of reasons. Laboratory experiments have demonstrated that the transmission efficiency of HIV is low. The few population based studies that have included children aged 5 to 12-14 years have found very low numbers of HIV infection in this age group while HIV prevalence abruptly increases in those age groups where sexual activity is initiated. And last but not least there is no correlation between population rates of HIV infection and of hepatitis C, the latter being nearly exclusively transmitted through injections. In conclusion, available evidence supports that the predominant mode of transmission of HIV in sub-Saharan Africa is heterosexual intercourse. This begs two important questions. If sexual intercourse between men and women is the predominant mode of HIV transmission in sub-Saharan Africa why are there large differences in HIV prevalence between different regions? And secondly: why are the HIV epidemics in sub-Saharan Africa so severe compared to other regions in the world?

5. Determinants of the heterosexual spread of HIV

The probability that a person becomes infected with HIV during a sexual contact is the product of the probability that a susceptible individual has intercourse with an infected individual and the probability that during this sexual encounter the virus is transmitted. Table

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3 gives an overview of the main factors that influence these probabilities.\(^1\) The rate of spread of HIV in a population is the result of a complex interplay between these factors and it is to be expected that in populations where HIV is spreading rapidly, risky sexual behaviour patterns and/or factors that enhance the transmission of HIV during sexual intercourse will be more prevalent than in populations where the rate of spread of HIV has been slower.

### Table 3 Possible determinants of the spread of HIV infection

<table>
<thead>
<tr>
<th>SEXUAL EXPOSURE TO HIV</th>
<th>TRANSMISSION OF HIV</th>
<th>INFECTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual behaviour</td>
<td>• Sexual practices</td>
<td></td>
</tr>
<tr>
<td>• rate of partner change</td>
<td>• Condom use</td>
<td></td>
</tr>
<tr>
<td>• sexual mixing patterns</td>
<td>• Classical STIs</td>
<td></td>
</tr>
<tr>
<td>• extent of concurrent partnerships</td>
<td>• Circumcision</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Hormonal contraception</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Viral strain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Genetic factors</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Other factors ?</td>
<td></td>
</tr>
</tbody>
</table>

### Sexual behaviour

A high rate of sexual partner change has been found to be associated with an increased risk of HIV infection, in numerous studies from different regions in sub-Saharan Africa.\(^2\) In addition, several studies have identified sex with a commercial sex worker as a risk factor for HIV infection in men.\(^3\)

The role of sexual mixing patterns in determining the rate of spread of HIV in populations has mainly been studied with mathematical models. Results from simulations with mathematical models suggest that patterns of sexual behaviour whereby men have sex with a

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small group of highly sexually active women, such as commercial sex workers, and some contacts with low activity women, lead to explosive epidemics.\(^1\) Also, extensive mixing between different age classes, i.e. when young women have sex with men who are much older than themselves, would enhance the rate of spread of HIV in the population. More recently it has been suggested that for the same rate of partner change concurrent partnerships are more efficient for the propagation of the virus than serial sexual relationships and that a pattern of concurrent partnerships in the population enhances the probability of an explosive epidemic.\(^2\) This is explained by the fact that the virus does not “waste any time” between partners.

**Factors that influence the transmissibility of HIV during sexual intercourse**

Studies on HIV discordant couples in Europe and the US have found sexual intercourse during menses to be associated with an increased risk of HIV infection in male partners of female index cases, but not in female partners of male index cases.\(^3\) In Europe and the US anal intercourse has been found to be strongly associated with HIV infection in women, even if couples infrequently engaged in it.\(^4\) Little is known about the practice of anal intercourse in sub-Saharan Africa, but there is a taboo on it and it is believed to be uncommon. Intercourse with a dry and tight vagina, so called “dry sex”, has been described as a fairly common sexual practice in many parts of the Democratic Republic of Congo, Zambia, Zimbabwe, Kenya and Uganda, as well as in Senegal, Mali, Benin and Ivory Coast.\(^5\) About one third of women interviewed in Lusaka (Zambia) occasionally engaged in this practice, by using intravaginal substances or mopping up vaginal secretions with a cloth.\(^6\) It is biologically plausible that this practice is associated with an increased risk of infection, because of bruising of the genital mucosa. In Zambia such association has been suggested in univariate analysis of risk factors for HIV infection in women,\(^7\) but among Kinshasa sex workers there was no evidence of an increased risk.\(^8\) Thus the role of this sexual practice in the spread of HIV in sub-Saharan Africa is far from clear. In conclusion, some sexual practices like anal intercourse are

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6. Nyirenda, “Study” (see previous note).
associated with a marked increase in the risk of HIV infection but are thought to be uncommon in sub-Saharan Africa. For other practices including “dry sex”, the risks are less well documented. In order to be a major determinant of the spread of HIV in a population, sexual practices need not only to enhance the transmission of HIV, but also to be common.

Condom use is considered one of the most cost-effective interventions to reduce the spread of HIV. A meta-analysis on data from studies on HIV discordant couples found that condom use may reduce the risk of HIV transmission by as much as 69%. Results from a simulation exercise drawing on data from a cohort study in southwest Uganda, suggest that a substantial proportion of HIV infections, up to 39%, could have been averted in the 1990’s if men had used condoms consistently with their one-off sexual contacts. Throughout the 1980’s and 1990’s condoms were used by less than 1% of married couples in the majority of African countries. Following HIV prevention campaigns condom use has increased in many countries, but this increase most likely came too late to be a major determinant of the differences in HIV prevalence between different regions in sub-Saharan Africa.

It is now established that other sexually transmitted infections (STIs), including ulcerative STIs as well as gonorrhoea and chlamydial infection, facilitate the transmission of HIV infection during sexual intercourse and can play a key role in the dynamics of HIV epidemics. So called classical STIs have been found to enhance the susceptibility of HIV uninfected individuals and the infectiousness of HIV infected individuals. Evidence for the facilitating role of classical STIs in the transmission of HIV was first provided by epidemiological studies on risk factors for HIV seroconversion and later confirmed by a controlled intervention trial which found a 40% reduction in HIV incidence in the general population of Mwanza Region, Tanzania following improved case detection and management of STIs. Studies in pregnant women and in female sex workers in sub-Saharan Africa have shown that the prevalence of STIs can be very high in certain African populations and that there can be large variations in prevalence and mix of STIs between different regions in Africa. There are several possible explanations for the variation in STI prevalence rates, including: (a) differences in sexual behaviour, i.e. rate of partner change and sexual mixing patterns; (b) differences in access to and use of effective treatment; (c) variations in the prevalence of other factors that may increase the risk of STIs such as lack of male circumcision and genital hygiene.

Male circumcision may have a direct effect on the probability of HIV transmission, as well as an indirect effect. The inner surface of the foreskin is rich in Langerhans’ cells that have

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HIV receptors and that are thus entry points for HIV infection, so that men lacking a foreskin would be less susceptible to HIV infection. In addition, uncircumcised men would be more susceptible to infection because of small abrasions of the foreskin, greater proneness to balanitis and higher susceptibility to ulcerative STIs. A meta-analysis of twenty-seven studies on the association between male circumcision and HIV infection in sub-Saharan Africa has provided convincing evidence for a reduced risk of HIV infection in men who are circumcised.

It has been suggested that the use of hormonal contraception is a risk factor for the acquisition of HIV infection by women. However, it remains unclear whether hormonal contraception is truly a risk factor for HIV infection or whether the association is confounded by behavioural factors. But even if the use of hormonal contraception were shown to increase women’s susceptibility to HIV infection it is unlikely to be a major explanatory factor for the spread of HIV in sub-Saharan Africa because it is used by only a minority of women.

HIV is characterised by a high genetic variability. There are two types HIV-1 and HIV-2 and three groups of HIV-1 (M,N and O). Both HIV types and all three HIV-1 groups are found in sub-Saharan Africa. All nine subtypes of HIV-1 as well as five out of the nine known circulating recombinant forms (CFRs) have been isolated from patients in Africa. There is strong epidemiological evidence for a higher transmissibility of HIV-1 compared to HIV-2. Whether there are also differences in transmissibility between different HIV-1 subtypes and CRFs is not clear. So far there is no convincing evidence that there exist major differences in transmissibility and pathogenesis between HIV-1 strains that may determine differences in rate of spread of HIV between different populations.

In 1996 the first report was published on a small group of sex workers in Nairobi who appeared to be resistant to HIV infection despite repeated exposure to the virus. The exact mechanism of this resistance is still unclear. However, so far no genetic factor has been found

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5. The human immunodeficiency viruses belong to the genus of the lentiviruses. “Lenti” meaning slow these viruses establish chronic infections. There are two human immunodeficiency viruses, HIV-1 and HIV-2. HIV-1 is subdivided in three groups (M, N and O). Group M is by far the most important as only a few individuals have been found to be infected with group N or group O. HIV-1 group M viruses are classified into nine subtypes on the basis of their genome. Among viruses belonging to a particular subtype, variations in the genome encoding for the envelope do not exceed 30%. Over the years more and more viruses have been identified that are recombinants, i.e. viruses with a genome that is a combination of two or more subtypes. Some of these recombinants have been quite successful and are by now widespread. These recombinants are called “circulating recombinant forms”.
that confers resistance against HIV infection and that is prevalent enough in a population to have an impact on the rate of spread of HIV.

It has been suggested that nutritional deficiencies, in particular vitamin A, may enhance disease progression and transmission of HIV infection.1 But two randomised trials on the effects of vitamin A supplementation on mother-to-child transmission of HIV-1 found no evidence for a protective effect of vitamin A supplementation.2

6. The multi-centre study on factors determining the differential spread of HIV in four cities in Africa

Using the framework presented in Table 3, a study was designed to explore possible reasons for the differences in rate of spread of HIV between different regions in sub-Saharan Africa. The study was conducted in four cities by a multidisciplinary team.3 In two of the cities, Cotonou in Benin and Yaoundé in Cameroon, the prevalence of HIV infection was relatively low (below 5% at the time the study was designed), in the two other cities, Kisumu in Kenya and Ndola in Zambia, the HIV prevalence was over 20%. It was hypothesised that in the two cities with high HIV prevalence risky sexual behaviour would be more common than in the cities with relatively low HIV prevalence and/or that factors that enhance the per sex act transmission probability, such as other STIs, would be more prevalent.

The study was a population based study and in each of the four cities a representative sample of about 1000 men and 1000 women aged 15 to 49 years was taken. Selected men and women were visited in their homes and asked for their informed consent. Consenting men and women were interviewed about their socio-demographic characteristics and sexual behaviour, including details about their sexual partners of the past year. They were also asked to provide blood samples and urine samples for testing for HIV and other STIs. In addition men were interviewed and examined on their circumcision status and women were asked to provide a swab with vaginal secretions to be tested for trichomoniasis. Apart from the study in the general population there was also a survey among sex workers. First a census was conducted of women who were self acknowledged sex workers. From the list of bars, brothels, hotels etc a representative sample of female sex workers was then taken. Sex workers who gave their informed consent to participate in the study were interviewed and tested for HIV and other STIs.

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3 The members of The Study Group on Heterogeneity of HIV Epidemics in African Cities were: A. Buvé (coordinator), M. Laga, E. Van Dyck, W. Janssens, L. Heyndrickx (Institute of Tropical Medicine, Antwerp, Belgium); M. Caraël (UNAIDS); S. Anagonou (Programme National de Lutte contre le SIDA, Benin), M. Laourou (Institut National de Statistiques et d’Analyses Economiques, Bénin), L. Kanhouou (Centre de Recherche en Reproduction Humaine et en Démographie, Bénin); L. Zekeng (Programme de Lutte contre le SIDA, Cameroon), E. Akam, M. de Loenzien (Institut de Formation et de Recherche en Démographiques, Cameroon), S.-C. Abega (Université Catholique d’Afrique Centrale, Cameroon); M. Kahindo (formerly National AIDS/STD Control Programme, Kenya), J. Chege, N. Rutenberg (The Population Council, Nairobi), V Kimani (Department of Community Health, University of Nairobi); R. Musonda, T. Sukwa, F. Kaona (Tropical Diseases Research Centre, Zambia); B. Auvert, E. Lagarde (INSERM U88, Paris, France); N.J. Robinson (formerly INSERM U88, Paris, France); B. Ferry, N. Lydié (Centre français sur la Population et le Développement, Paris, France); R. Hayes, L. MorisonWilliams, H. Weiss, J. Glynn (London School of Hygiene and Tropical Medicine).
Table 3 shows the HIV prevalence in each of the four cities by age and sex. The HIV prevalence was higher in women than in men, except in Cotonou: the ratio of the HIV prevalence in women to the HIV prevalence in men was 1.03 for Cotonou, 1.9 for Yaoundé, 1.5 for Kisumu and 1.38 for Ndola. The difference in HIV prevalence between men and women was especially striking in Kisumu and Ndola in the age group 15 to 19 years. In this age group in Kisumu the HIV prevalence in women was more than 6 times higher than in men (23% vs 3.5%) and in Ndola more than 4 times higher (15.4% vs 3.7%). Sexual behaviour as reported by young women alone could not explain the observed differences in HIV prevalence between young women and young men and it is believed that there are biological factors, such as genital herpes infection, that play an important role in increasing the vulnerability of young women to HIV infection.

Table 4 Prevalence of HIV infection by age group, sex and city

<table>
<thead>
<tr>
<th></th>
<th>COTONOU</th>
<th>YAOUNDÉ</th>
<th>KISUMU</th>
<th>NDOLA</th>
</tr>
</thead>
<tbody>
<tr>
<td>MEN</td>
<td>N = 928</td>
<td>N = 896</td>
<td>N = 622</td>
<td>N = 624</td>
</tr>
<tr>
<td>15 - 19</td>
<td>0</td>
<td>0</td>
<td>3.5%</td>
<td>3.7%</td>
</tr>
<tr>
<td>20 - 24</td>
<td>2.3%</td>
<td>1.4%</td>
<td>12.3%</td>
<td>13.2%</td>
</tr>
<tr>
<td>25 - 29</td>
<td>6.7%</td>
<td>3.1%</td>
<td>28.7%</td>
<td>27.3%</td>
</tr>
<tr>
<td>30 - 39</td>
<td>3.9%</td>
<td>9.9%</td>
<td>33.1%</td>
<td>39.6%</td>
</tr>
<tr>
<td>40 - 49</td>
<td>3.8%</td>
<td>5.7%</td>
<td>27.7%</td>
<td>25.8%</td>
</tr>
<tr>
<td>All</td>
<td>3.3%</td>
<td>4.1%</td>
<td>19.8%</td>
<td>23.2%</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>(2.3 – 4.8)</td>
<td>(3.0 – 5.7)</td>
<td>(16.8 – 23.2)</td>
<td>(20.0 – 26.8)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>WOMEN</th>
<th>N = 1015</th>
<th>N = 1017</th>
<th>N = 893</th>
<th>N = 910</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 - 19</td>
<td>2.4%</td>
<td>3.4%</td>
<td>23.0%</td>
<td>15.4%</td>
</tr>
<tr>
<td>20 - 24</td>
<td>3.8%</td>
<td>9.3%</td>
<td>38.3%</td>
<td>41.8%</td>
</tr>
<tr>
<td>25 - 29</td>
<td>4.8%</td>
<td>11.2%</td>
<td>37.1%</td>
<td>43.8%</td>
</tr>
<tr>
<td>30 – 39</td>
<td>3.5%</td>
<td>8.9%</td>
<td>30.1%</td>
<td>34.8%</td>
</tr>
<tr>
<td>40 – 49</td>
<td>2.6%</td>
<td>6.1%</td>
<td>18.5%</td>
<td>20.4%</td>
</tr>
<tr>
<td>All</td>
<td>3.4%</td>
<td>7.8%</td>
<td>30.1%</td>
<td>31.9%</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>(2.4 – 4.8)</td>
<td>(6.2 – 9.6)</td>
<td>(27.2 – 33.3)</td>
<td>(28.9 – 35.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FEMALE SEX WORKERS</th>
<th>N = 275</th>
<th>N = 320</th>
<th>N = 296</th>
<th>N = 319</th>
</tr>
</thead>
<tbody>
<tr>
<td>(95% CI)</td>
<td>57.5%</td>
<td>34.4%</td>
<td>74.7%</td>
<td>68.7%</td>
</tr>
<tr>
<td></td>
<td>(51.4 - 63.3)</td>
<td>(29.2 – 39.9)</td>
<td>(69.2 - 79.4)</td>
<td>(63.2 - 73.6)</td>
</tr>
</tbody>
</table>


Possible population risk factors for a rapid spread of HIV that were explored included:

a) exposure to an HIV infected partner through sexual behaviour, i.e.
   - age at first sexual intercourse;
   - marriage patterns (age at first marriage, pre-marital relations, number of spousal partners...);
   - rate of partner change (lifetime number of sex partners, number of non-spousal partners in the past year);
   - contacts with sex workers;
   - age difference between sex partners (spousal and non-spousal);
   - condom use.

b) factors that enhance the transmission of HIV during sexual intercourse:
   - prevalence of other sexually transmitted infections, including gonorrhoea, chlamydial infection, syphilis, genital herpes and (for women) trichomoniasis;
   - lack of male circumcision.

In addition a study was done on the distribution of different HIV-1 strains in the four populations.

Table 5 summarises the distribution of the main risk factors for HIV infection that were explored.1

<table>
<thead>
<tr>
<th>Parameters of sexual behaviour</th>
<th>Consistently more common in the high HIV prevalence sites</th>
<th>NOT consistently more common in the high HIV prevalence sites</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>young age at first sexual intercourse (women)</td>
<td>high rate of partner change</td>
</tr>
<tr>
<td></td>
<td>young age at first marriage</td>
<td>sex with sex workers</td>
</tr>
<tr>
<td></td>
<td>large age difference between spouses</td>
<td>concurrent partnerships</td>
</tr>
<tr>
<td></td>
<td></td>
<td>large age difference between non-spousal partners</td>
</tr>
<tr>
<td>Co-factors in HIV transmission</td>
<td>HSV-2 infection</td>
<td>non-ulcerative STI’s</td>
</tr>
<tr>
<td></td>
<td>Trichomoniasis (women)</td>
<td>(gonorrhoea and/or chlamydial infection)</td>
</tr>
<tr>
<td></td>
<td>lack of male circumcision</td>
<td>syphilis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>dry sex</td>
</tr>
<tr>
<td></td>
<td></td>
<td>lack of condom use</td>
</tr>
</tbody>
</table>

High rates of partner change were not more common in the two high HIV prevalence cities than in the two “low” HIV prevalence cities. Also contacts with sex workers, concurrent partnerships and large age differences between partners, were not more common in Kisumu and Ndola than in Cotonou and Yaoundé. With the possible exception of contacts with sex workers these risk behaviours were more common in Yaoundé, one of the “low” HIV prevalence cities, than in the high HIV prevalence cities. Levels of condom use reported by men were similar in the four cities, but women in the “low” HIV prevalence cities reported less frequent condom use than women in the high HIV prevalence cities. The only parameters of sexual behaviour that distinguished Kisumu and Ndola from Cotonou and Yaoundé, were age at sexual debut of women and age at first marriage of men and women. Compared to the

“low” HIV prevalence cities women in the high HIV prevalence cities started sexual activity at a younger age, and men and women got married earlier.

These data on sexual behaviour suggest that the differences in epidemic spread of HIV between the East African cities and the West African cities cannot be explained by differences in sexual behaviour patterns alone. However we do have evidence that there are important differences in the probability of transmission of HIV during sexual intercourse, between the high HIV prevalence cities and the low HIV prevalence cities. In the “low” HIV prevalence cities nearly all men were circumcised, whereas in the high HIV prevalence cities the majority of men were not circumcised. In addition ulcerative sexually transmitted infections, especially genital herpes, and trichomoniasis were more prevalent in Kisumu and Ndola than in Cotonou and Yaoundé. In Cotonou 13% of men had HSV-2 or syphilis, in Yaoundé 29%, in Kisumu 37% and in Ndola 40%. The corresponding figures for women were 31%, 52%, 69% and 58%.

As for circulating strains of HIV-1, subtype A was found to be the most prevalent subtype in the “low” HIV prevalence cities as well as in one of the high HIV prevalence cities, Kisumu. Subtype C, the predominant subtype in Ndola, has been found in the past in Cameroon as well. This suggests that differences in circulating subtypes of HIV-1 are not a major factor in determining the rate of spread of HIV in sub-Saharan Africa.

In conclusion in the four African populations that were studied differences in risky sexual behaviour were outweighed by differences in factors influencing HIV transmission probability, i.e. lack of male circumcision and ulcerative STIs, in particular HSV-2 infection and syphilis. This study has – once more – highlighted the importance of factors other than sexual behaviour in shaping HIV epidemics in sub-Saharan Africa.

7. Why are the epidemics in sub-Saharan Africa so severe compared to other continents?

By the end of the year 2003, 7.5 to 8.5% of adults in sub-Saharan Africa were estimated to be HIV infected. Other regions in the world that are heavily affected are the Caribbean region with a prevalence among adults estimated at 1.9 to 3.1%; Eastern Europe and Central Asia with 0.5 - 0.9% of adults infected, mainly through intravenous drug use; and South and South East Asia where 0.4 to 0.8% of adults are infected. Estimates of numbers of people living with HIV in South and Southeast Asia range between 4.6 and 8.2 million. As such this region is the region in the world with the second highest number of people living with HIV. There is a lot of concern that the HIV epidemics in this region may become as severe as in sub-Saharan Africa.

As there are no truly comparative data on sexual behaviour and other risk factors for HIV infection from different continents, it is very difficult to predict what the course of the HIV epidemic will be in other populations than the African populations where the predominant mode of HIV transmission is heterosexual intercourse. Some cautious comparisons however can be made between sub-Saharan Africa and Southeast Asia.

The HIV epidemics in most parts of Africa started about ten years earlier than in Southeast Asia, but this is unlikely to fully explain the differences in HIV prevalence in the general population. For instance, in South Africa and in Thailand the HIV epidemics started around the same time, in the early 1990’s. By 1997 the HIV prevalence in the general population was 12.9% in South Africa and 2.2% in Thailand.

It seems that sex between men and female sex workers is prevalent in many parts of Africa as well as in Southeast Asia. In the multicentre study on factors determining the differential spread of HIV in four African cities, the proportion of men in the general population who declared at least one contact with a sex worker in the past year ranged between 3% in Kisumu and 12% in Yaoundé, but these figures are considered as grossly underestimated.1 In a nation wide survey in Thailand 24.2% of men in urban areas and 9.5% in rural areas reported commercial sex in the previous year.2 Sexual behaviour of Cambodian men appears to follow a similar pattern.3 By way of comparison, in Western Europe the proportion of men who reported having paid for sex in the past year, ranged between 0.5% in Great Britain and 4.7% in Portugal. An outlier was Spain where 9.9% of men reported having paid for sex in the past year.4 Moreover condoms have been in use by sex workers in Europe long before HIV infection was introduced in these populations.5 What makes the difference then between sub-Saharan Africa and Southeast Asia?

First, large scale interventions to promote condom use with sex workers that were supported at the highest political level, were initiated earlier in the course of the HIV epidemic in Thailand and Cambodia than in most of sub-Saharan Africa. In Bangkok, Thailand, in 1996, 97% of brothel based sex workers and 78% of “indirect sex workers” reported consistent condom use with all their clients.6 In Cambodia the interventions were started later but by 1999 78% of brothel based sex workers reported consistent condom use with all their clients.7 This is in contrast to what sex workers reported in 1997 in the multicentre study: in Yaoundé and in Ndola 28% of sex workers reported condom use with their last client, in Kisumu 50% and in Cotonou 69%.8

A second important difference however between sub-Saharan Africa and Southeast Asia is the extent to which male clients of sex workers have intercourse with non-commercial female partners who in turn have sex with several other male partners. Surveys in several countries in Southeast Asia, including Singapore, Sri Lanka, Thailand and Cambodia, showed that in general unmarried women are not sexually active.9 In contrast in sub-Saharan the percentage of unmarried women who reported at least one sexual partner in the past twelve months ranged between 2% in urban areas in Togo and 64% in rural areas in Guinea Bissau.10 As such it seems unlikely that we will see in Southeast Asia the same high HIV prevalence rates among young women, which are seen in several countries in sub-Saharan Africa and which

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8 Sittitrai et al., “A survey of Thai sexual behaviour and risk of HIV infection”.
10 Caraël, “Sexual behaviour”.
are driving the HIV epidemics. This may however change very quickly if the sexual behaviour of young women in Southeast Asia changes under the influence of socio-economic developments and the adoption of modern lifestyles.

8. Conclusions

This paper explored reasons for the severity and the heterogeneity of the HIV epidemics in sub-Saharan Africa, from an epidemiological perspective. The spread of HIV in a population is the result of a complex interplay between sexual behaviour and biological factors that enhance the transmission of HIV - even in populations where there is only one predominant mode of transmission, as is the case in sub-Saharan Africa. Sexual behaviour patterns are shaped in a specific cultural and socio-economic context. Several cultural and socio-economic features of African societies conspire to enhance the vulnerability of African populations to HIV, including the subordinate position of women, impoverishment, rapid urbanisation and modernisation, and last but not least wars and conflicts. Associations between HIV infection and socio-economic status have been documented at the individual level since the mid 1980's. Unravelling associations at the population level proved more difficult. A World Bank study from 1995 found a relationship between the spread of HIV infection at the population level and four societal variables including per capita GNP, inequality of income distribution, ratio of urban males to females and male-female literacy gap.\(^1\)

HIV epidemics in their turn lead to increased poverty; break down of social services and of the social fabric of society. They threaten further the respect for human rights if fear leads to inappropriate actions that ignore the rights of individuals, whether or not they are HIV infected. In this way societies that are facing a severe HIV epidemic may be trapped in a vicious circle. The only way out is to acknowledge the wider contextual factors of the spread of HIV and to take these into account in the design of control programmes. This reasoning has led to dissolution of the Global Programme of AIDS of the World Health Organisation in 1995, and the creation of UNAIDS, the Joint United Nations Programme on HIV/AIDS which brings together nine United Nations system organisations in order to provide promote a multisectoral approach to the HIV/AIDS pandemic.

The decline of social services, including health services and education, represents so many missed opportunities to stem the spread of HIV. The persistently high prevalence of STIs, such as syphilis, in certain populations, is the result of a failing health system. The breakdown of the education system represents a missed opportunity to provide young people with the knowledge and skills necessary to lead a healthy sexual life.

AIDS: A Darwinian Event?

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**Introduction**

The HIV/AIDS epidemic is the biggest natural event in the history of our species for the last 500 years. Professor Roy Anderson, who has modelled the likely path of the epidemic, estimates that HIV/AIDS is a 130-year event.¹ This, we contend, is an underestimate. HIV/AIDS has already put an indelible mark on the most-affected societies and that effect will certainly be felt for generations. In addition, Anderson’s model – like all such mathematical exercises – measures what can be measured, leaving other factors as hypothetical zeros. The HIV/AIDS epidemic is a complex systemic change in human ecology. It is unleashing secondary impacts that have demographic and epidemiological consequences, which in turn create feedback loops into the dynamics of the epidemic itself.

HIV/AIDS is certainly an historic event. It may also be a “Darwinian event”. We argue historians have two particular responsibilities with regard to this epidemic. Firstly history should provide us with ideas, paradigms and methodologies for understanding and responding to the disease. Secondly there is an awful predictability about HIV/AIDS and what it has the potential to do. Historians have the experience of seeing an event of unparalleled significance unfold before their eyes. To some extent this history can be written in advance as wake-up call as to what might happen. Certainly there must lessons from the past which we can apply to this epidemic.

To date historians have not generally engaged with the HIV/AIDS epidemic and we are not sure why. Perhaps because thinking has been premised on the assumption that it is “just another epidemic”. Comparisons with the Black Death abound. This can mislead. AIDS won’t kill such a large proportion of the global population as the fourteenth century catastrophe, nor will it do it with the same speed. In some settings though mortality may over time approach that experienced in parts of Europe. There are two significant differences: AIDS mortality will take place over decades so mortality of any given cohort will exceed levels experienced in all but history’s most severe demographic disasters; and secondly AIDS selects for age and gender, the majority of those dying are between 25 and 50, with more women than men falling victim.

In this article though we shall focus primarily on the idea of AIDS event of such magnitude and with such implications that it assumes the proportions of “a Darwinian event”. What does it mean to describe something as a Darwinian event? It is a provocative but, we hope, a productive idea to interpret the HIV/AIDS pandemic in this way. We need however to begin with some definitions. In the context of this paper:

* AIDS is the Acquired Immuno-Deficiency Syndrome, the name given to the grouping of diseases caused by the Human Immuno-Deficiency Virus (HIV). The disease was first recognised only in 1981.
* Darwinian means that process of evolution by natural selection as first described by Charles Darwin. Here we mean that there is a struggle for survival in each generation; there is individual variation in the population; and the variation has an hereditary component. All this means that there will be gradual variation in a population with those characteristics associated with greater survival ability dominating.
* An event is shorter term than a process. In this context an event is something where we can clearly say “this happened and had these effects”. The classic example of a Darwinian event is the pollution arising from the industrial revolution resulting in the dark form of peppered moths (Biston betularia) predominating over the light form.

The Darwinian framework provides a powerful set of hypotheses for the evolution of both the HIV/AIDS epidemic and human responses to it. It raises far more issues than can possibly be addressed in a short chapter. At this point, the most that we can attempt is to put forward our ideas and hypotheses to stimulate debate, inspire disciplines new to the study of the epidemic to research the epidemic and its consequence, and postulate the value of this approach to understanding the HIV/AIDS pandemic. We hope historians will be among those who engage.

The framework for analysis

In this chapter we shall pursue the Darwinian hypothesis to its limits. This requires us to apply versions of universal Darwinism to social phenomena. This is not a resuscitation of social Darwinism, but a wider application of Darwinian principles, as they are currently understood in the scientific community. We recognise this is hard to grasp in dealing with a disease like AIDS, and all the baggage it carries, – as Dawkins says “nature is not cruel, only pitilessly indifferent. This is one of the hardest lessons for humans to learn. We cannot admit that things may be neither good nor evil, neither cruel nor kind, but simply callous – indifferent to all suffering, lacking all purpose”. Let us begin by identifying different possible interpretations and then following through on the logic.

(a) The principle of natural selection is the most famous of Darwin’s ideas, and the subsequent discovery of genetic inheritance and DNA, means this too is closely identified

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1 We are well aware of the rich debate about Darwin and Darwinism elegantly evidenced in writing of Stephen Jay Gould, Stephen Pinker, Richard Dawkins and many others, and the existence of Darwinian discussion groups such as that at the London School of Economics http://www.lse.ac.uk/Depts/CPNSS/darwin/. Our use of the term Darwinian is intentional.

2 Before 1845 near Birmingham peppered moths were primarily light-coloured, but some had darker wings and were called the melanic or carbonaria forms. Prior to the industrial revolution bird ate the darker moths – they were easier to see. In the 1850s, about 98% of the uneaten peppered moths were the light variety. Industrialisation meant trees darkened and so birds more easily ate the light moths. By the 1950s, 98% of the peppered moths were the dark variety. Some argue this is a “proof of evolution”, others say there can be light-peppered moths and dark-peppered moths,—but they are all still peppered moths, variations within a single species. http://www.pathlights.com/ceencyclopedia/09nsel05. html#Peppered%20Moths We would accept the argument that this was the beginnings of an evolution that would change peppered moths. Ironically the clean air acts reversed this in the 1950s.

with genetic selection. A “Darwinian event” could be one where those that pass on their genes are selected for certain genetic traits. The converse is that those who die before they breed successfully are also “selected”: they are selected out. This is the “survival of the fittest” scenario, during which Homo sapiens undergoes what Oppenheimer calls “the mangle of near extinction”, resulting in a post-mangle population that has significant genetic differences from that which existed beforehand.¹ We will ask, below, whether HIV/AIDS fits this scenario. We would note here one important point: survival of the fittest does not mean survival of the strongest or most “intelligent”, it means survival of the best adapted.

(b) Darwinism is commonly associated with biology’s replicator, genes. However, natural selection is a principle of evolution and not a specifically genetic theory. Any systematic encoder of information that has the traits of replicability, fecundity and durability, along with a degree of imperfection or variation in offspring, can serve as a Darwinian replicator. While genes are biology’s replicator, memes are a “second replicator” operating where there are human brains that can host them.² Any significant cultural or technological change (especially with regard to communications) has an impact on the replication and hence “evolution” of memes. Within this vast area, we focus on memes that have a direct impact on survival and reproduction, and higher-level complex social memes such as religions and organisational systems.

(c) Lastly, we have to look not just at Homo sapiens as an organism but also as part of an ecological framework. Thus, a “Darwinian event” could be a change in the ecological or evolutionary framework within which Homo sapiens exists. We exist not just as a species but as part of the web of nature, a web that includes the entire biosphere from microbes to ecosystems—and also our social environment. Under this “ecology change” scenario, a “Darwinian event” for humankind can be a change in that framework that affects us, leading us into a new collective adaptation. We will see that any genetic or memetic adaptation is necessarily an ecological change.

This paper will study each of these in turn. Each provides a fruitful point of departure for understanding the likely trajectory of the HIV/AIDS epidemic and assessing if it is indeed a Darwinian event.

Why HIV?

HIV is a retrovirus, meaning that it is one of the first known viruses to transcribe DNA (Deoxyribose Nucleic Acid) from an RNA (Ribose Nucleic Acid) template.³ In order to exist, the virus has to enter a cell and insert itself into the cell’s DNA to reproduce itself. Viruses can only infect and take over a cell if a proper “receptor” is present.

In order for infection to occur, the virus has to enter the body and attach itself to host cells. HIV attacks a particular set of cells in the human immune system known as CD4 cells. Once the virus has entered the CD4 cell, it is safe from the body’s immune system. The virus particles replicate inside the cell and eventually break out of it. In the process, they destroy the cell before going on to infect more CD4 cells. Thus, the immune systems of infected people are gradually weakened until they fall prey to a host of diseases which they would normally fight off.

HIV is hard to transmit. The main modes of transmission, in order of importance, are: unsafe sex, transmission from infected mother to child (an infected mother has a 30% chance

³ The science around the AIDS virus is clearly explained in many books and articles – one of the most accessible is Christopher Wills, Plagues (London, Flamingo, 1997).
of passing the infection to the child), intravenous drug use with contaminated needles, and use of infected blood or blood products. There have been a small number of infections involving accidents with contaminated medical equipment and other body fluids, but these are rare.

The fact that heterosexual transmission is the main way in which HIV is transmitted, followed by mother-to-child transmission may have far reaching implications. Evolutionary theorists argue that our primary function is to reproduce and our existence is geared towards this end. The fact that sex, conception and birth – so fundamental to reproduction – is central to the transmission of this disease, may have physical, social and psychological implications for our species. We do not explore this but suggest it deserves attention.

HIV is a simple virus, replicates rapidly and so can mutate equally rapidly. The long incubation period means that people are infectious for many years, but most do not know that they are infected. A pathogen must transmit its progeny from one host to another. Success may come from taking a long time to disable the host, giving plenty of time for contact with other potential victims; surviving for a long time outside the body; and being easily transmissible. HIV falls in the first category. Other diseases that have hit the headlines are Ebola and SARS (Severe Acute Respiratory Syndrome). Ebola kills within a week and does not survive outside the body. SARS has a number of characteristics that made it potentially dangerous: the virus survives outside the body; it has a relatively long incubation period, but fortunately for humankind it was not easily transmissible.¹

AIDS will not wipe out people in the way western diseases killed the “immunologically naïve” indigenous populations of the Americas, Australasia and parts of Africa from the middle of the last millennium. Lacking defences against common European diseases such as smallpox, typhus, measles and influenza, these populations fell ill faster and diseases were more virulent. The result was massive depopulation – whole peoples disappeared and others were so seriously depleted as to have been written out of history.

Documentation of this process begins with Columbus’s landfall on the Caribbean island of Hispaniola. In 1492 at the time of his arrival, there were perhaps a million Taino people. A disease akin to smallpox appeared in 1519 and by 1550 the Taino were extinct.² This pattern of devastation was repeated throughout the Caribbean and in the Aztec and Inca kingdoms. The troops of the Spanish conquistador Hernán Cortès brought smallpox. It is estimated that the population of Mexico fell from 25.2 million in 1518 to 1.1 million in 1605. Similarly affected were the Inca to the south and native American populations to the north. There, Spanish explorers had encountered a vibrant culture with towns and temples in the Mississippi valley. By the early 1700’s this had vanished along with most of the people.³ The loss of 95% of the indigenous population of the Americas, along with their civilizations, was a Darwinian event par excellence. The role of disease in human history has been charted by a number of authors: initially by McNeil⁴ who argues that disease is key, and more recently by Diamond⁵, who sees disease as part of broader geographical determinism. The interaction of disease, famine and political crisis has also been investigated, notably with regard to the “late Victorian holocausts” that overtook the emergent third world in the last quarter of the 19th century.⁶ From these experiences we can identify a nexus of complex disaster, with different factors including climate, epidemic disease, conflict and social disorder all reinforcing one

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¹ http://www.people.virginia.edu/~rjh9u/darwmed.html accessed on 29/6/04.
² Sheldon Watts, Epidemics and History: Disease, Power and Imperialism (New Haven, Yale University Press, 1997), 88.
another to cause a decline in life expectancy and population stagnation and, in some cases, population collapse. These are cases of populations under severe stress, but how selection pressures might operate so that we could fairly describe such events as “Darwinian”, remains speculative.

It is clear from the history of epidemics that there are some populations at sub-regional, regional or continental level which are more susceptible to infection. There are also subtypes in a population who are more likely to be infected. Does this also apply to HIV/AIDS? If it does then the argument that AIDS is a Darwinian event is supported.

It has been suggested that at the population level those whose ancestors experienced the plague may be genetically resistant to HIV. The plague bacillus attached to the same receptor on the cell that HIV attaches to. If this were the case then mapping the plague and movement of people whose genes carry this measure of protection would allow us to predict where the most serious HIV epidemics will and won’t be experienced. It might help explain why the genetically naïve populations of sub-Saharan Africa are experiencing such a severe epidemic.1

In the early days of the epidemic it seemed that, within populations, some income/occupation groups were more likely to be adversely affected than others. Initially AIDS spread among those with higher incomes. This is well documented in the World Bank book Confronting AIDS. In Kagera, Tanzania, the probability of dying from AIDS was higher for women with primary or secondary education than for those with no education. In the late 1980s a study of workers in two businesses in Kinshasa found those with higher incomes were more likely to be infected. The reason postulated was that men with higher incomes and education could more easily attract and support additional partners including sex workers.2

More recently AIDS appears to be increasingly a disease of the poor and marginalised. What this means for humankind needs to be explored. We don’t know if the disease will have a greater impact on certain groups – are entrepreneurs in business and political leadership also more likely to be entrepreneurial in their sex lives? Will HIV disproportionately affect them and will this have any impact on our gene pool? In work done as a scenario building exercise for Shell South Africa we noted that some populations were experiencing higher levels of infection than others, with people in particular areas and particular occupation groups at high risk. Newly prosperous people are often at risk, as are sex workers, mobile workers, soldiers, miners and others in hazardous occupations, as well as the unemployed. Those who habitually think only in the short-term are at high risk. Figure 1 was developed in a Scenario planning exercise for Shell South Africa.3

Is there any validity in this? Those who survive the epidemic long enough to breed successfully create the future gene pool. As Dawkins notes “To the extent that differences between individuals are due to genes (which may be a large extent or a small one), natural selection can favour some quirk of embryological origami or embryological chemistry and disfavour others”.4 A characteristic influenced by genes – thinking in an entrepreneurial manner or being sexually attractive – can be favoured or disfavoured by natural selection. If it increases the chance of passing the genes on (through successful breeding) then these genes may be passed on, at the expense of others.

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The Demographic Impact of HIV/AIDS

We would argue that AIDS is a Darwinian event because of its demographic impact. It is a demographic shock. Demographic consequences are felt in a number of ways, but most immediately through increased mortality and decreased fertility. In a scientific meeting on Demographic and Socio-Economic Impact of AIDS, in Durban in 2003, available evidence was assembled and assessed. “In the worst affected countries the probability of a 15-year old dying before reaching the age of 60 years has risen dramatically, from a range of 10 to 30% in the mid-1980s, to a range of 30 – 60 % at the turn of the century”¹.

Population size and structure

Mortality rises among those infected. Five community based studies in east Africa found mortality among infected adults was 10 to 20 times higher than for uninfected adults.² Child mortality rises both among HIV-positive children, infected through mother to child transmission (in the absence of treatment most HIV infected children dies before their fifth

birthday\textsuperscript{1}, and among HIV negative children who have an infected mother. A summary of the key demographic impacts of this disease is shown in Table 1. This data is taken from the normally conservative United Nations.

Table 1. Summary of Estimated and Projected Impact of HIV/AIDS on Mortality Indicators\textsuperscript{2}

<table>
<thead>
<tr>
<th>Indicator</th>
<th>53 countries where HIV/AIDS impact included in 2002 UN estimates\textsuperscript{3}</th>
<th>7 countries with prevalence &gt; than 20%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of deaths (millions)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Without AIDS</td>
<td>159</td>
<td>174</td>
</tr>
<tr>
<td>With AIDS</td>
<td>170</td>
<td>207</td>
</tr>
<tr>
<td>Percentage difference</td>
<td>7</td>
<td>19</td>
</tr>
<tr>
<td>Life expectancy at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Without AIDS</td>
<td>63.9</td>
<td>68.4</td>
</tr>
<tr>
<td>With AIDS</td>
<td>62.4</td>
<td>64.2</td>
</tr>
<tr>
<td>Percentage difference</td>
<td>2.4</td>
<td>6.1</td>
</tr>
<tr>
<td>Child mortality rate (per 1000)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Without AIDS</td>
<td>93.9</td>
<td>68.8</td>
</tr>
<tr>
<td>With AIDS</td>
<td>98.8</td>
<td>75.8</td>
</tr>
<tr>
<td>Percentage difference</td>
<td>5.3</td>
<td>10</td>
</tr>
</tbody>
</table>

Only in the very worst affected countries (the UN report specifically mentions Botswana, Lesotho and South Africa) is the population expected to start declining after 2005. This is due to increased mortality, reduced fertility and the disruption of society. Infected women are less likely to fall pregnant and carry a child to term, and premature mortality means there will be fewer women of child bearing age. Writing about the Caribbean post Spanish conquest, Italian demographer Massimo Livi-Bacci ascribes part of the demographic collapse to economic and social collapse, exploitation of labour, decline in the number of women, mobility and concubinage.\textsuperscript{4} This should have resonance for Africa today. For Uganda it was estimated that the number of births was reduced by approximately 700,000, corresponding with almost 5.9\% of all births that would have occurred during the last two decades.\textsuperscript{5} Cohort mortality may be very high. Figure 2 looks at life-expectancy for today’s 15-year-olds boys in a number of African countries\textsuperscript{6}.

\textsuperscript{1} Marie-Louise Newell, Heena Brahmbhatt and Peter D Ghys, ‘Child Mortality and HIV infection in Africa: a review’, in Zaba, Whiteside and Boerma, ‘Demographic and socio-economic impact of AIDS’, article quoted in the previous footnote.

\textsuperscript{2} United Nations Secretariat, Department of Economic and Social Affairs, Population Division, \textit{The impact of AIDS}, ESA/P/WP.185 2 September 2003.

\textsuperscript{3} These countries are listed in the report and include the USA, Russian Federation, India and China.


According to these conservative analyses, in countries where 15% of adults are currently infected, around a third of today’s 15-year-olds will die of AIDS. Where adult prevalence rates exceed 15%, the lifetime risk of dying of AIDS is much greater. In countries such as South Africa and Zimbabwe, where a fifth or a quarter of the adult population is infected, AIDS is set to claim the lives of around half of all 15-year-olds. And, in Botswana, where about one in three adults is already HIV-infected – the second highest prevalence rate in the world – it is estimated that two-thirds of today’s 15-year-old boys will die prematurely of AIDS.

In South Africa the Medical Research Council has tracked the steady increase in deaths using the death certificates collected by the South African Department of Home Affairs. South Africa is one of the few countries where there is death registration and in 2000 over 90 percent of adult deaths were registered. Between 1998 and 2003 there was a 150 percent increase in deaths of women aged 20 – 49 years, and this is adjusting for population growth and possible improvement in registration.1

An increase in mortality is also recorded for young people. In Botswana under-five mortality is expected to have risen to 104 per thousand live births, in absence of AIDS it was projected to decrease to 45 per 1000 live births. AIDS causes the majority of these “extra” deaths.2

The structure of the population will change both in terms of age cohorts but also in gender ratios. Life expectancy for women is worse affected than that for men. We know that there are more women infected than men, in sub-Saharan Africa women are 30 percent more likely to be infected than men, and this is even more marked at younger ages. A 15 – 24 year old woman is 3.4 more times more likely to be infected than their male counterparts.3 In some settings this will amplify existing gender issues, for example the current gender selection biased to boy children, which has been particularly reported from parts of Asia.

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Orphaning

The increase in orphaning is a demographic impact but it will have social and economic consequences. UNICEF estimates that by 2010 an estimated 20 million children in Africa will have lost one or both parents to HIV/AIDS. However it is not just the numbers that is important. We also need look at affected children as a percentage of all children. UNICEF estimates that in some settings up to 25% of children may be orphaned. For over 80 percent of orphans in the worst affected countries the cause will be HIV/AIDS. These children face severe stress, they are less likely to attend school, more likely to be exploited and experience premature mortality, and they also have a more pessimistic outlook on life.\footnote{UNICEF, *Africa’s Orphaned Generation* (New York, UNICEF, 2003).} Life expectancy and child mortality rates have been widely used as markers for improvements in the welfare of populations. In Botswana, life expectancy at birth is now estimated to be 39 years instead of 71 without AIDS. In Zimbabwe, life expectancy is 38 instead of 70. In fact, children born today in several Southern and East African countries have life expectancies below 40.

We would argue that demographic impact of this magnitude is certain to have far reaching economic, social and political consequences. Will these also be Darwinian? Perhaps, and it is certainly something we need to consider and it would merit thought by other disciplines.

Survival of the Fittest?

Human beings evolved in Africa several hundreds of millennia ago. Our genome evolved in response to the constraints and opportunities of that environment. Indeed, the entire theory of evolution is premised on historical contingency and the possibility of novelty. There can be a new species, and there can also be an extinction, and even a single new species or extinction can reshuffle the whole deck of phenotypical\footnote{The visible characteristics of an organism resulting from the interaction between its genetic makeup and the environment.} cards.

Could a pathogen such as HIV wipe out the entire human race? The theoretical possibility is there, but such a pathogen would have to possess remarkable microbial and epidemiological characteristics. Currently, neither HIV nor the headline hitting Ebola and SARS fit this bill. Notable is that disease is given short shrift in Martin Rees’ doomsday prognoses for the human race.\footnote{Martin Rees, *Our Final Century: Will the Human Race Survive the Twenty-First Century?* (London, Heinemann, 2003).} Rather, Rees sees our main collective threat as our own technology run amok, or sufficiently abusing the planet to make it uninhabitable.

The pre-historical record suggests that in fact, the main threats we have faced (and faced down) in our evolutionary past have been associated with climatic change and catastrophic events such as major volcanic eruptions. We evolved three million years ago in Africa, and spread across Asia and Europe, developing into several different archaic species, including Neanderthals. *Homo sapiens* evolved more recently in Africa (about 150,000 years ago) and crossed into Asia just 80,000 years ago. All today’s variation in stature, skin colour, hair and teeth type, has occurred within these eighty millennia.

There is plentiful evidence that genetic factors can influence susceptibility and virulence. Micro-biologists have investigated a range of genetic factors that predispose to infectious diseases. Janis Hutchinson lists ten specific chromosomes that help determine these with respect to HIV/AIDS.\footnote{Janis Hutchinson, ‘HIV and the Evolution of Infectious Diseases’, in George Ellison, Melissa Parker and Catherine Campbell (eds.), *Learning from HIV and AIDS* (Cambridge University Press, 2003), 44.} If we take into account the opportunistic infections that accompany HIV, then the number will be higher.
Mutual adaptation between *Homo sapiens* and pathogens has occurred through one of three channels. The first is through immunity acquired at the level of the individual (and thus acquired anew every generation). Examples include measles and smallpox.

A second channel is the extinction of the pathogen itself by burn-out in its intermediate hosts. A probable case of this is the plague, which may well have died out in Europe because it killed rats too quickly. Burn-out in intermediate hosts does not apply to HIV/AIDS.

A third is the evolution of the pathogen itself into a less virulent form. A likely, though still disputed case of this is syphilis, which showed exceptional virulence in its first century. It has been widely noted that emergent diseases have particularly florid manifestations in their first few years, after which they reduce in virulence. It is an epidemiologist’s rule of thumb that the first epidemic to strike a virgin population is the most devastating. In the case of HIV/AIDS, the way this would operate is that a certain genetically-specified sub-group within the population would be “rapid progressors”, developing AIDS within two or three years of contracting HIV. These individuals would demonstrate particularly extreme symptoms (of opportunistic infections) and would be more likely to die off before they can transmit the virus onwards.

One implication of the recent character of our common ancestry is that, as a species we lack genetic diversity, and hence suffer greater collective susceptibility to infectious diseases. Most epidemic infectious diseases have emerged since the invention of agriculture in the last ten thousand years, associated with population density and proximity to domestic animals.¹ This is a very short time period for genetic selection to operate.

For various reasons, HIV seems especially unlikely to succumb to evolutionary pressure for lower virulence. For a pathogen to be sustainable in a population, for every currently infected host there must be a greater-than-one chance of infecting a new host. In epidemiologists’ algebraic parlance, $R_0$ must be greater than one. For many infectious diseases such as measles, cholera and whooping cough, $R_0$ is in the tens. For HIV, it is only slightly above one. But the fact the disease has a high degree of lethality and the host is infectious for many years, means that this low transmission ratio is sustainable. HIV also has a high rate of mutation and recombination, and uses the human immune system to replicate itself. In summary, this means that “HIV may be evolutionarily free of constraints that reduce its virulence and increase its susceptibility”.²

In theory HIV could reach saturation in a host population, infecting and killing every individual, without jeopardising its onward transmission. In such a process, in the host population there could be selection for the genetic traits that make for slow progression from HIV to AIDS. But this is unlikely to be significant because of the mode of transmission and the fact that the virus is not easily transmitted. In most populations there will be those who are not exposed to infection (don’t have sex, stick to one partner who sticks to them) and those who will simply not be infected (30 percent of couples are discordant meaning that one is infected and the other is not). Any selection pressures would take generations to work through.

Because of the unique way in which HIV causes immuno-suppression, it also has other implications for the evolution of pathogens and their human host. A human population with a large proportion of immuno-compromised individuals is a new eco-system for infectious diseases, marked by greater ease of transmission of infectious agents, and lesser vulnerability to the human immune system. The current pandemic of TB is an example of this, but there is no reason why epidemics of other infectious agents should not also seize

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upon this opportunity. Given the normal functional relationship between transmissibility and virulence, this would imply that infectious agents would (mostly) evolve in the direction of higher transmission levels but lower virulence.

Concluding this tour d’horizon of the genetic evolutionary implications of HIV/AIDS, it is evident that the pandemic has intriguing, novel and potentially far-reaching impacts. Some models for the impacts of HIV/AIDS imply immense adverse outcomes, and others imply modest impacts. Thus far, empirical data to substantiate models are scarce. They are novel, because of the peculiar capacity of HIV to retain its lethality, which means that we face the need for a new kind of accommodation to a pathogen. They are far-reaching, because HIV/AIDS will be with us for generations, and it may change our entire disease environment.

“Memetic Evolution”

What are “memes”? The human brain has the capacity for receiving, encoding and transmitting information. Replicable bits of information are “memes”. Insofar as the packets of information have a capacity for replication (like genes themselves), they will do so, and thus become replicators along a new dimension. Having a capacity for variation and recombination, they are themselves able to evolve in a Darwinian manner. Simple examples of memes are tunes, games and the skills necessary to make shoes; examples of complex combinations of memes (or memeplexes) are religious beliefs. There is no special reason why DNA should be the sole Darwinian replicator: any information coding system can do it.

Dawkins sets out a chronology of life explosion which has ten thresholds. The first is the “replicator threshold” where some self copying system occurs. Thresholds two to seven are: the Phenotype Threshold; the Replicator Team Threshold; the Many-Cells Threshold; the High-Speed Information Threshold; the Consciousness Threshold; and the Language Threshold. His eighth Threshold is the Co-operative Technology Threshold – he says: “Indeed it is possible that human culture has fostered an entirely new kind of self-replicating entity – the meme” 1.

Susan Blackmore describes the gene-meme relationship as like a man walking a dog: at first the dog (memes) is on a tight leash, but increasingly it is able to steer its former master, so that it is not clear who is in charge. Memeticists describe the relationship between memes and genes as purely an analogy, but it is one that allows us to lend some analytic rigour to the interaction of society and biology in the context of HIV/AIDS. Also, insofar as we are exploring the limits of HIV/AIDS as a “Darwinian event”, the least we can do is give the hypothesis the best run for its money.

This section analyses two memes that are especially relevant to the case of HIV/AIDS: male circumcision and risk-taking.

Male Circumcision

An instance of a meme that features prominently in the literature, is male circumcision. This was cited by Richard Dawkins in his introduction to Susan Blackmore’s The Meme Machine 2, with reference to his old school:

[A] Martian geneticist, visiting the school during the morning cold bath ritual, would have unhesitatingly diagnosed an “obvious” genetic polymorphism. About 50 per cent of the boys were circumcised and 50 per cent were not. The boys, incidentally, were highly conscious of the polymorphism and we classified ourselves in Roundheads versus Cavaliers.... It is, of course, not a genetic but a memetic polymorphism. But the Martian’s

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mistake is completely understandable; the morphological discontinuity is of exactly the kind that one normally expects to find produced by genes.

In England at that time, infant circumcision was a medical whim, and the Roundhead/Cavalier polymorphism at my school probably owed less to longitudinal [inter-generational] transmission than to differing fashions in the various hospitals where we happened to have been born – horizontal memetic transmission, yet again. But through most of history circumcision has been longitudinally transmitted as a badge of religion (of parents’ religion, I hasten to point out, for the unfortunate child is normally too young to know his own religious mind.) Where circumcision is religiously or traditionally based, the transmission will follow a longitudinal pattern of heredity, very similar to the pattern for true genetic transmission, and often persisting for many generations. Our Martian geneticist would have to work quite hard to discover that no genes are involved in the genesis of the roundhead phenotype.

Unlike, for example, tattooing or navel piercing, circumcision is a meme that is less often widely transmitted horizontally.

This particular meme is important to our case because male circumcision appears to protect against HIV transmission by as much as a 40% reduction in risk. In short it is a meme that has come to provide a very clear survival advantage to its possessors. Until now, its replicatory capacity has been related almost wholly to its attachment to certain religious and cultural memes or “memeplexes”. But in the era of AIDS, circumcision now also provides a survival advantage.

This is of both theoretical and practical interest. The protective effect of male circumcision should logically result in populations that practice it suffering lower HIV rates than those that do not, and thus surviving better. It could also result in the meme of male circumcision itself being adopted by other populations – i.e. spread horizontally. Also relevant is to ask what determines circumcision in a society. The circumcision meme is closely associated with religious beliefs, and these may in turn be associated with other social practices that are correlated with HIV risk. Examples might include polygamy and early marriage of girls.

**Risk-Taking**

Another memetic trait is propensity to take risks. In the field of sexual behaviour, this has been studied, concluding that there is a genetic basis to unfaithfulness to one’s partner. But it is also a gene-meme interaction, with some individuals or subgroups more prone to risk-taking than others on the basis of their genetic profile.

In the absence of HIV/AIDS or a similar STI, risk taking in the field of sexual encounters, especially numbers of sexual partners, is genetically adaptive. Men who have higher numbers of partners will have more offspring. Women who have illicit affairs are more likely to select those kinds of men as lovers, and to conceive children as a result of such casual flings, rather than through regular sexual intercourse with their long-term partners, and as many as 10% of all children in western societies are not in fact fathered by their “fathers”.\(^1\) This helps point to a genetic basis for the different jealousies of men and women. Men are genetically concerned with their partners’ faithfulness in a physical sense, because they don’t want to be bringing up children that are not their own. Women are genetically unconcerned with their partner’s physical unfaithfulness, because it does not effect the survival of their own children, but are concerned with any emotional affection that accompanies any such cheating, because this may be a prelude to abandonment.

If there is a “cheating gene”, many of us are likely to have it. Is sexual risk-taking also associated with other forms of risk-taking such as entrepreneurship? There is much suggestive anecdote about the sexual appetites of leading politicians and businessmen. On the other

hand, reproductive egalitarianism is a conspicuous feature of human societies, and as such is likely to have both genetic and memetic bases.\(^1\) This, the counterpart of sexual adventurism, may also be evolutionarily selective.

There is some historical-anthropological evidence on which to build a theory of memetic change. Many Melanesian and some native American societies were, in Marshall Sahlins’ formulation, “Aphrodisian”, in their traditions of sexual generosity, including routinely offering sexual favours to guests, traders and diplomats. The arrival of western explorers, missionaries and traders unleashed catastrophic epidemics on these societies, including syphilis. The low fertility, high mortality, and the sheer disfigurement and suffering caused by the disease contributed to population plunges and a thorough-going social demoralisation.\(^2\) These societies simply could not adapt their sexual practices quickly enough to deal with threat of STIs.

In the era of AIDS, sexual risk-taking undoubtedly increases risk of HIV, and as such negatively selects for survival. This is a new phenomenon in the history of our species. As a result, we can anticipate a new dynamic between natural and sexual selection.

Christian fundamentalists are, strictly speaking, correct in advocating that the A and B of AIDS prevention (abstinence and faithfulness to one lifetime partner) are sufficient, spurning the C for condoms. In the absence of condoms or other preventive technologies, over the generations, those who faithfully pursue the A and B would survive, while the rest of humanity would become steadily less numerous. The efficacy of A and B would be strongly associated with their connection to other memetic factors, notably religious faith, implying that such a hypothetical society would be much more religious.

**Implications**

The cases of potential memetic “evolution” in response to HIV/AIDS point to the complexity of the impacts of the epidemic. No part of human life is untouched. Some memes have clear advantages or disadvantages for survival—and may as a consequence be selected for. How long this will take, we cannot speculate. The impacts of the epidemic compel human populations to explore elements of their wired-in behavioural capacities that have not recently been in evidence (such as selfishness under energy stress). Other memes, have their own autonomous logics, which may prevail despite their maladaptation to the realities of the epidemic.

**“Ecology Change”**

The preceding discussion has necessarily veered away from simple evolutionism into examining the role of individual human host, human society and the HIV in a complex framework that encompasses all. Any change to one part of the system necessarily impacts on others. To this extent, many “ecological” issues have already been addressed. Others follow. For example, as Barnett and Blaikie observed in Uganda in the late 1980s, HIV/AIDS causes changes in land use, which in turn have other consequences for agrarian society.\(^3\) This is an example of the way in which it is necessary to analyse HIV/AIDS as an historic event.

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The question that remains is, how does HIV’s adaptation to its host and *Homo sapiens*’ response to HIV interact with one another? What future will be jointly created by our genes and memes, and HIV and its parallel and inter-linked evolution?

Let us begin with HIV, as it is in the driving seat. As mentioned, HIV has unique evolutionary features, which enable it to bypass or render ineffective the pressures for lower virulence. This occurs at various levels, from the microbial to the collectivity of the host population. It is a fractal characteristic. At the population level, the key factor is the 7-10 year time lag between HIV infection and the development of AIDS, which enables $R_0$ to be sustained without loss of lethality.

We know that HIV is evolving. It does this by mutation and recombination, creating new strains that have differing transmissibility, virulence and vulnerability to treatments. The most likely outcome of genetic change in HIV is to increase resistance to treatment and to increase $R_0$ by increasing the transmission rate. In populations already at saturation level (above 40% adult prevalence) the latter might be a maladaptive trait, insofar as a new variant of HIV that achieved still higher levels of prevalence among young women would actually begin to create a below-replacement fertility regimen in the host population. In evolutionary terms, this is a credible scenario.

Turning to the human response to HIV, we can identify three main types of reaction. The first is the impact of the epidemic on social functioning, including poverty, food security and social reproduction. Aspects of this have been explored above. An additional element to the “new variant famine” hypothesis, first put forward by de Waal and Whiteside is the way in which responses to the stress of hunger and destitution become maladaptive in the context of HIV/AIDS. This is because survival strategies such as migration or commercial sex work increase the risk of HIV transmission. This is perhaps the most alarming implication of the “new variant famine” hypothesis: that it has a feed-back loop into HIV transmission itself, helping to sustain high prevalence. If it occurs – and thus far we have only anecdotal evidence that it does – this would be a far-reaching revision to the Roy Anderson projection of AIDS as a 130-year event.

Another potential feedback loop is the adverse impact of lower levels of girls’ education on HIV risk. Educational performance is declining because of children being withdrawn from school to help with sustaining the household (especially the case for girls), and because of the lower standards of schools that are stricken with high educator morbidity and mortality. Low female educational achievement is in turn associated with higher risk of HIV.

It is a commonplace of population history that a demographic shock such as a famine or war creates greater vulnerability to a second shock such as an epidemic. Disasters rarely come singly. What is different about HIV/AIDS is that it is a long-wave event, with structural implications for human ecology, which in turn implies that its secondary impacts will themselves be structural and sustained.

We could, in short, see a new viral-human ecologic framework in which HIV saturation combines with poverty, hunger and social dislocation in a new kind of socio-epidemiological trap. Populations that pass a threshold of compounded distress, may simply be unable to recover. In a globalised world, ambitious individuals can escape and live elsewhere, bringing up their families in richer low-HIV societies, leaving the poorest and most entrapped populations to continue a downward spiral of misery. A bifurcation of global life chances along these lines, determined in large part by HIV prevalence, cannot be ruled out.

The second human response to HIV is the medical-scientific response. In two decades, scientists have learned more about HIV than almost any other pathogen. But, in the absence
of a magic bullet, what has this meant for the virus? History counsels us to be cautious about the impact of human intervention—including medical science—on the life of a pathogen.

Some of the medical responses to HIV/AIDS, such as anti-retroviral therapy (ART) may in fact be prove to be adaptive for the virus. It would do this if ART extends the infective period of the person living with HIV, and thereby increases the number of his or her risky sexual encounters, by a greater degree than it reduces infectivity. If the proportional increase in the life expectancy of the PLWHA (People living with HIV/AIDS) from the moment of infection on ART is A, and the proportional decrease in infectivity (though lower viral load) is B, then if A exceeds B, then $R_0$ increases. Note that this assumes no change in sexual behaviour: simply living longer implies more sexual partners. In addition, there are some indications that the availability of ART may also increase risky behaviour, because HIV becomes seen as a treatable condition. On the other hand, the VCT associated with ART provision may lead to behaviour change in the opposite direction, lowering transmission.

ART is not, therefore, a block to the odyssey of HIV. It brings many desirable outcomes, such as prolonging the lives of those living with HIV and AIDS, and potentially blunting some of the disastrous secondary impacts such as reducing the numbers of children orphaned by AIDS. But this is managing or containing the epidemic, not halting it.

The third human response is what we may call the “political economic” response: the whole cluster of institutional measures put in place to manage and (optimistically) solve the problem posed by HIV/AIDS. International institutional responses have their own independent logic, driven by the need to appear to managing the problem in such a way that the institutions themselves are protected and can reproduce themselves. This subject warrants a detailed discussion in its own right, bringing to bear the sociology of public service institutions. As is usual with unsolvable problems, the United Nations has dutifully become repository for international efforts, so that it can be blamed for any lack of success.

Scanning human responses to HIV/AIDS, what we see is the extent to which we have already adapted to accommodate the killer in our midst. We are sharing our habitat with HIV, and our society, institutions and even our prized science are quietly accommodating this specialist predator.

Conclusion

In June 2004 the Copenhagen Consensus project released their list of priorities for the ten great global challenges. “These challenges, selected from a wider set of issues identified by the United Nations, are: civil conflicts; climate change; communicable diseases; education; financial stability; governance; hunger and malnutrition; migration; trade reform; and water and sanitation.” The panel of economic experts was asked to address this and decide the best ways of advancing global welfare, especially that of developing countries, supposing an additional $50 billion of resources was available. The AIDS epidemic was identified as the first priority: “The panel assigned the highest priority to new measures to prevent the spread of HIV/AIDS. Spending assigned to this purpose would yield extraordinarily high benefits, averting nearly 30m new infections by 2010. Costs are substantial, estimated at $27 billion. Even so, these costs are small in relation to what stands to be gained. Moreover, the scale and urgency of the problem—especially in Africa, where AIDS threatens the collapse of entire societies—are extreme”. (ibid)

Writing in 1987, when the implications of the HIV/AIDS epidemic were first being absorbed by the scientific community, the evolutionary theorist Stephen Jay Gould wrote:

The evolutionary perspective is correct, but utterly inappropriate for our human scale. Yes, AIDS is a natural phenomenon, one of a recurring class of pandemic diseases. Yes, AIDS may run through the entire population, and may carry off a quarter or more of us. Yes, it may make no biological difference to Homo sapiens in the long run: there will still be plenty of us left and we can start again. Evolution cares as little for its agents—organisms struggling for reproductive success—as physics cares for individual atoms of hydrogen in the sun. But we care. The atoms are our neighbors, our lovers, our children, and ourselves. AIDS is both a natural phenomenon and, potentially, the greatest natural tragedy in human history.¹

Seventeen years later, we have no reason to dispute his verdict that we care, but there is evidence stacking up to suggest this may make a biological difference to Homo sapiens.

We asked if HIV/AIDS was a Darwinian event. We looked at the evidence and suggested that its demographic consequences were such that, for this reason alone, it merits this description. However it has social and economic consequences as well.

This paper was originally presented at an historical conference. We concluded that AIDS is an event of historical significance, not least because we must respond to it in a (short) historical time frame. Thus, it is high time that new disciplines become engaged in looking at the epidemic, drawing comparisons from other epidemics and demographic disasters, and applying frameworks from evolutionary science. Historians can both contribute to the debate and help us influence our future. George Orwell wrote: “He who controls the past commands the future. He who commands the future conquers the past”. This is worth thinking about.

Cattle Breeders and the Spread of AIDS in the Lake Chad Basin

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Introduction
Since its appearance at the beginning of the 1980s the AIDS epidemic has posed one of the greatest challenges to development and social progress in the world. HIV infection has grown exponentially in many countries. Cultural, economic and political phenomena have been blamed for this evolution. Expression currently in use such as “disease of poverty” or “disease of development” evoke the scope of the problem by indicating that AIDS is not limited to questions of sexual behaviour or questions of health.1

Sub-Saharan Africa has the highest level of HIV infection in the world. In Central and Western Africa it is between 4% and 13%.2 In some countries in this region, the level of infection has remained stable whilst in others, such as the Lake Chad basin, it reaches almost 14%.3

With dithering and delays, these countries have expressed – through political leaders, researchers, civil society and NGOs – the desire to undertake research and intervention efforts in various projects so as to identify the causes of the epidemic and to find appropriate responses.

This article will attempt to present and explain the spatio-temporal spread and the evolution of AIDS in the Lake Chad basin by examining the situation of cattle breeders who practise seasonal movement of livestock. Our starting point is 1985 when the level of HIV in the region had barely attained 1%. It was then that the first cases of AIDS were detected. It was in this year, also, that Cameroonian authorities set in place the National Committee for the Fight against HIV/AIDS (CNLS) and that similar committees were established in neighbouring countries.

Nineteen years after the creation of the CNLS and five years after the establishment of an initiative by the Lake Chad basin countries, under the aegis of UNAIDS, the level of HIV continues to rise. In Cameroon, for example, the following HIV levels have been observed: less than 1% in 1985, 1% in 1990, 1,5% in 1991, 2% in 1992, 3% in 1993, 5,5% in 1994, 7,7% in 1999 and 11,8% in 2001. In the Central African Republic the figures are as follows: 6,8% in 1999 and 12,9% in 2004.4

4 Lazare Kaptue, “Adolescents and AIDS”, in B. Kuate-Defo (ed) Sexuality and Reproductive Health during Adolescence in Africa with Special Reference to Cameroon (Ottawa, University of Ottawa Press, 1998), 261-
I put forward the hypothesis that cattle breeders are involved in the spread of AIDS for a variety of reasons: low level of education, the adoption of at risk behaviours like unprotected sex, sharing of razor blades and the practice of scarification, poor access to information, no access to modern health care, relative ignorance of AIDS and insufficient and inappropriate awareness campaigns.

**Geopolitics and geography of the Lake Chad basin**

At a geopolitical level, the commission of countries of the Lake Chad basin is a sub-regional body for the rational management of renewable and non-renewable resources which are relatively rare. It deals mainly with water resources in an area known as the Chad Convention Basin, created on 12 May 1964 by four countries: Cameroon, Niger, Nigeria and Chad. The Central African Republic joined in 1994. The basin has since covered an area of 966,955km².

![Fig 1. Lake Chad basin: position and the main countries involved.](image)

The Lake Chad basin, figured in the above sketch, is a geographical complex whose delimitation and definition is vague. It is made up of portions of five countries: northern Cameroon, northern Nigeria, northern Central African Republic, southwestern Chad and southeastern Niger. This area has several human and physical assets at its disposal. The variety of its rivers and the diversity of its contours can be exploited for human activities. The manner in which the different role-players are involved in health matters is of particular interest. The physical and human environments of the countries included in this area are varied. Cameroon has climatic conditions which are milder from every point of view than those of its neighbours with relative equilibrium between the wet and dry seasons, quality grazing and water supplies. These favourable conditions explain the constant population movements towards Cameroon. The phenomenon of flow and displacement of breeders goes back to the first half of the twentieth century. It was then that the Peuls/Foulbès, the main cattle breeding tribes, settled in the region. The migration of these breeders does not follow a regular itinerary. It is difficult to follow them through the tracks on the plains, the valleys and

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the hills. Family records from the east of Niger studied by Paul Thibaud\textsuperscript{1} show that in 1984 the breeders took the southern route towards pastures in Nigeria and Cameroon that had dried out after the flooding of Lake Chad. This permanent migration between regions and countries modifies the social life of the people involved.

Is it not possible to determine a relationship between the herders’ continual movement and the spatial spread of AIDS by examining this geographical space with its complex dynamics?

I shall attempt to link the geography of health to that of the cattle in order to study the role of the breeders in the spatial dynamic of the AIDS epidemic. This approach, based on long periods of observation of the territory and collection of statistical data, will, on the one hand, enable one to record determining factors and the role of the breeders in the spread of AIDS and, on the other hand, to grasp the causes for the increase of HIV in the sub-region.

The spread of AIDS is described in current publications by WHO and UNAIDS as well as in thematic articles which reveal the differences between the countries of the south and those of the north regarding the spatial spread of the disease and access to care. However, studies on the movement of people have concentrated on at risk populations such as truck drivers and refugees.\textsuperscript{2} They also focus on areas where people mix (market places, train and railway stations).

This brief bibliographic survey should not lead to the belief that the players, the factors and the mechanisms which contribute to the spread of AIDS in sub-Saharan Africa are well known. Studies on the various sectors exist,\textsuperscript{3} but very few of them have concentrated on the spread of HIV amongst the breeders of the Lake Chad basin. The difficulty in gaining access to the grazing areas due to the savannah, dangerous animals, lack of staff and financial problems have hampered research on breeders as an at risk group since 1985. Much remains to be done and this article hopes to make a contribution in this direction.

\textbf{Methodology}

Data was collected through interviews and field observations which took into account local specificities for the region under consideration.\textsuperscript{4} We took the following variables into account: region of provenance, age, sex, level of education, matrimonial status, AIDS knowledge, access to information and to health care. We also questioned the people on their sexual behaviour: the number of sexual partners outside marriage during the preceding twelve months, the number of sexual partners during the transhumance\textsuperscript{5} in the preceding twelve months, the frequency of sexual relations and the use of condoms.

\textsuperscript{4} During the months of December 2002, January, March and April 2003 in areas of Ngaoundéré plateau, the Bénoué basin, in the Mandara mountains and the banks of the “oxbow of Chad” we organised twenty focus groups according to socio-professional categories. There were a total of seventy-five focus groups. Each focus group brought together a dozen breeders which resulted in a total of nine hundred breeders being questioned.
\textsuperscript{5} Transhumance is the seasonal moving of livestock to another region.
The study was based on a sample of approximately a thousand breeders. The size of the sample was seen as necessary to assess the facts with sufficient precision. The initial count was 1250 but because of various drop outs, it was reduced to 1053 by the time that field work began. The group consisted of breeders amongst whom there were 392 owners of cattle, 458 paid herders and 203 family helpers (Table 1). The people interviewed came exclusively from the main Cameroonian areas of transhumance such as the yaeré of Logone, the Waza reserve, the surrounding areas of Lake Chad, Logone and Chari.

Table 1  Distribution of migrant breeders according to socio-professional categories

<table>
<thead>
<tr>
<th>Cattle owners</th>
<th>Salaried herders</th>
<th>Family helpers</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>392</td>
<td>458</td>
<td>203</td>
<td>1053</td>
</tr>
<tr>
<td>37.22%</td>
<td>43.49%</td>
<td>19.27%</td>
<td>99.98%</td>
</tr>
</tbody>
</table>

Our sample was limited to the 15-50 age bracket with 15 years being the age at which an individual in the breeding system is considered to have finished his apprenticeship in pastoral techniques under the tutelage of parents, and 50 being when a man is considered to be an expert because of the large number of expeditions in which he had taken part. The investigation took place between November 2002 and June 2003.

Our initial hypothesis was that the movement of the cattle and the herders who accompanied them in their grazing contributes to the spread of HIV/AIDS because of the adoption of at risk behaviours which are factors in the spatial spreading of HIV. We also believed that these diverse movements were caused by climatic disturbances and the unequal distribution of vegetation during the last few decades.

The movements of men and cattle in the Lake Chad basin

The Lake Chad basin is characterised by predominantly pastoral activity. The survival of the herds is determined by continual movement both in time and space. The rate of movement for man and beast is estimated at 80%. According to the Cameroonian breeding service, four different breeding patterns exist in the region, all orientated towards a traditional management style: total transhumance (45%), nomadic (10%), semi-transhumance (25%) and sedentary (20%).

Contrary to cattle owners in certain European countries who also practice pastoral breeding, those from Lake Chad do not resort to fixed breeding. This would require the use of expensive products such as oil cakes, fodder and mineral salts for feeding the cattle. Because of a lack of finances the Lake Chad cattle owners do not breed in one place and continue with transhumance. The movement of cattle is very diffuse. The migrations in the Lake Chad basin are what interest us. The phenomena of migrations do not allow for the breeders to be included in the local and country-wide programmes for the prevention of HIV/AIDS organised by national AIDS committees in the respective countries as well as by UNAIDS.
The breeders begin to move as soon as the rains stop. At this point grass resources lose their nutritional value. The flow of water diminishes and permanent watering places are further and further away. As Henri Frechou\(^1\) has pointed out, the dry season poses a serious problem for all the breeders, from the south to the north of the Lake Chad basin. Some of the areas make up for these climatic changes by having streams, lakes and natron water sources. In the vernacular these are the *yaéré* or the *laoré*. Along the edges of these stretches of water, as far as the eye can see, are vast stretches of flood plains covered in a carpet of green. They are a precious reserve that lasts into the heart of the dry season. These *laoré* are precious spaces where the breeders feed their cattle. Their disappearance would signify a growth in rural poverty. The areas which have such natural reservoirs are prized by the breeders who come from areas which do not provide similar bounties. They become their place of residence during the long months of the dry season, contributing to a growth in the local population. The breeders cover great distances in search of green pastures. It is impossible to evaluate these movements quantitatively but, generally speaking, they can be said to take place twice a year.

The itinerary followed by the breeders and their herds during the transhumance is not linear. It makes dangerous detours across mountains and plains, high ground and valleys. Time spent in one place depends on the men’s strength and the presence of resources.

The areas which are abandoned are those where grazing and water are absent over wide stretches at the beginning of the dry season, when the cattle are plentiful but weak. As a solution to this problem, the cowherds decide to move on. This is their reaction to the lack of vegetation and natron water sources. These departure areas are varied. The most important in Cameroon are the Bénoué basin, the northern plain of Diamaré, the high ground of Adamaoua, the plains around Mora, the Mokolo plateaus and the Gawar and Guinder basins.

During our study, we notice that the main areas to which the breeders trekked were the banks of the Benoué and its tributaries (Tiel, Kebbi, Rey, Faro and Déo), the Logone *yaéré* to the north of Pouss and the Waza reserve, Fianga Lake, Lère Lake as well as Lake Chad itself.

During the campaigns of cattle vaccination which take place each year the livestock is counted by employees of the cattle breeding service of Cameroon and that of neighbouring countries. According to figures supplied by this service and by SODEPA,\(^2\) there are 5.5 million heads of cattle in Cameroon and slightly more in Chad. These figures must be taken with a pinch of salt as many of the breeders refuse to declare the exact number of livestock for fear of being taxed. During transhumance, more than half the cattle are moved around during both the dry and the wet seasons. Only those animals which are too old or too young to trek the long distances remain in the village.

The movement of the animals requires large numbers of personnel, either permanent or temporary, to watch over them or to provide all sorts of care. It has been estimated that about 500,000 people are involved in pastoral activities. This means a considerable portion of the active population involved in breeding moves about. During the moving, the attitudes and behaviours of the departure areas are transported to the arrival areas. The breeders come from different areas and often different countries.

Table 2 shows the large number of cattle owners participating in the transhumance who along with family helpers are directly involved in watching over their herds in countries such as Nigeria, the Central African Republic and Chad. The number of herders is relatively low in these countries. This can be explained by the insecurity in the region which is characterised by, amongst other things, cattle rustling. Sometimes, the herders sell the cattle

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without prior permission from the owners. The owners prefer to watch over their herds as they have lost faith in their herders. In order to succeed in this difficult task, they surround themselves with family helpers. These people are direct members of the family. Paid herders are expensive with the cost being calculated according to the distance travelled and the risks faced. On the other hand, there are many herders amongst breeders in Cameroon. They are cheap to hire as the distances covered during the treks are relatively short.

Table 2: Distribution of migrant breeders according to spatial origin and to socio-professional categories

<table>
<thead>
<tr>
<th>Area</th>
<th>Owners</th>
<th>Herders</th>
<th>Helpers</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diamaré plain</td>
<td>35</td>
<td>125</td>
<td>23</td>
<td>183</td>
<td>17,37</td>
</tr>
<tr>
<td>Adamaoua plateaus</td>
<td>37</td>
<td>98</td>
<td>28</td>
<td>163</td>
<td>15,47</td>
</tr>
<tr>
<td>Bénoué basin</td>
<td>40</td>
<td>102</td>
<td>27</td>
<td>169</td>
<td>16,04</td>
</tr>
<tr>
<td>Nigeria</td>
<td>87</td>
<td>30</td>
<td>38</td>
<td>155</td>
<td>14,71</td>
</tr>
<tr>
<td>Central African Rep.</td>
<td>76</td>
<td>44</td>
<td>42</td>
<td>162</td>
<td>15,38</td>
</tr>
<tr>
<td>Southwestern Tchad</td>
<td>117</td>
<td>39</td>
<td>45</td>
<td>201</td>
<td>19,08</td>
</tr>
<tr>
<td>Niger</td>
<td>0</td>
<td>20</td>
<td>0</td>
<td>20</td>
<td>1,89</td>
</tr>
<tr>
<td>Total</td>
<td>392</td>
<td>458</td>
<td>203</td>
<td>1053</td>
<td>99,94</td>
</tr>
<tr>
<td>Percentage</td>
<td>37,23</td>
<td>43,49</td>
<td>19,28</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Breeders, overwhelmingly male, young, single and with low levels of education

In a recent survey on the relationship between HIV/AIDS and migrant miners in post-apartheid South Africa, Mark Lurie and colleagues noted that migration is an essentially male affair. This is also the case amongst the breeders in the Lake Chad basin. Only men move around all the time. They represent 97,7% of the sample studied. Table 3 shows the distribution of breeders by sex and geographic origin. There are few women constituting a percentage of 2,27% and a total of 24. Their activities are almost exclusively limited to cooking. Generally speaking, they remain at home and look after the children and the elderly and raise small stock (sheep, goats and poultry). Transhumance is largely a male dominated phenomenon.

Table 3: Distribution of migrant breeders according to sex

<table>
<thead>
<tr>
<th>Male</th>
<th>Owners</th>
<th>Herders</th>
<th>Family helpers</th>
<th>%</th>
<th>Female</th>
<th>Owners</th>
<th>Herders</th>
<th>Family helpers</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diamaré plain</td>
<td>35</td>
<td>125</td>
<td>18</td>
<td>16,9</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>0,47</td>
</tr>
<tr>
<td>Adamaoua</td>
<td>40</td>
<td>102</td>
<td>23</td>
<td>15,7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>0,37</td>
</tr>
<tr>
<td>Bénoué basin</td>
<td>37</td>
<td>98</td>
<td>22</td>
<td>14,9</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>0,56</td>
</tr>
<tr>
<td>Nigeria</td>
<td>87</td>
<td>30</td>
<td>33</td>
<td>14,2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>0,47</td>
</tr>
<tr>
<td>Central African Rep.</td>
<td>76</td>
<td>44</td>
<td>42</td>
<td>15,4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Southwestern Tchad</td>
<td>117</td>
<td>39</td>
<td>41</td>
<td>18,7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>0,37</td>
</tr>
<tr>
<td>Niger</td>
<td>0</td>
<td>20</td>
<td>0</td>
<td>1,89</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>392</td>
<td>458</td>
<td>179</td>
<td>97,7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>24</td>
<td>2,27</td>
</tr>
</tbody>
</table>

The 27-32 age category dominates the sample with 34.56%, followed by the 33-38 group and the 21-26 group (21.74% and 21.27% respectively); the 15-20 section represents 14.52% and the two others, namely 39-44 and 45-50 make up 5.31% and 2.56% respectively. Thus the youth and young adults are in the majority of the breeders involved in the transhumance. Their age groups represent 91.62% of the total. If a socio-professional categorisation approach is adopted, it can be seen that family helpers of the 15-20 age group dominate at 75.36% with a total of 153 people. This group is followed by that of young owners from the 27-32 age group (46.68%). Paid herders from the 27-32 age group are relatively well represented (39.51%).

The age groups concerned correspond to individuals who are of an age to have regular sexual contacts. Generally speaking, people between 15 and 35 years of age dominate in the majority of the migrations. They have the strength and energy to carry out the necessary hard work of cattle herding.

<table>
<thead>
<tr>
<th>Table 4</th>
<th>Distribution of workforce according to age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>Owners</td>
<td>0</td>
</tr>
<tr>
<td>Herders</td>
<td>0</td>
</tr>
<tr>
<td>Helpers</td>
<td>153</td>
</tr>
<tr>
<td></td>
<td>153</td>
</tr>
</tbody>
</table>

The migrant breeder tends to be single as this status favours mobility. A bachelor is not tied to any particular place. He is at that moment in life when he wishes to discover new things. He is prepared to leave for the ends of the earth in search of a hypothetical life of ease. In our study the majority of the herders were single: 57.64% out of 607 individuals who were questioned. Men who were separated from their spouses or companions came second (23.74%). Married men whose wives had remained in the villages constituted the smallest group (18.61%). The presence of a large number of herders who were bachelors and who were moving around allows one to postulate that there would be a strong link between their attitude and the spread of AIDS.

Generally speaking, bachelors, divorces and widowers – those who have no marital ties – enjoy greater freedom of movement and life style than the married breeders. They take very few precautions when faced with the risk of AIDS. Their relationships show great sexual freedom.

<table>
<thead>
<tr>
<th>Table 5</th>
<th>Distribution of migrant breeders according to their matrimonial situation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Married</td>
</tr>
<tr>
<td></td>
<td>Number</td>
</tr>
<tr>
<td>Owners</td>
<td>111</td>
</tr>
<tr>
<td>Herders</td>
<td>76</td>
</tr>
<tr>
<td>Helpers</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>196</td>
</tr>
</tbody>
</table>

1 Daniel Courgeau, Méthodes de mesure de la mobilité spatial, migrations internes, mobilité temporaire, navettes (Paris, Institut national d’études démographiques, 1988).
Three education systems exist in the region covered by this study: Koranic school, western schooling known as formal and the school of life where one is taught by relations and older children.

The western model of education is not widespread, to judge by the low number of breeders – 7.11% of the total – who recall having attended school during their childhood. The migrants have a very low level of formal education.

There is a larger percentage of breeders – 28.20% – who have received instruction at Koranic schools. Many decades ago, Pierre-François Lacroix noted that the percentage of Fulbe boys in the former Adamawa who had attended Koranic school was never lower than 15% and was often as high as 50%.¹

Life apprenticeship gained in the home environment appears to be the dominant means of access to knowledge in the region as it is mentioned by a large majority of the breeders – 64.76%, that is 681 members of our sample. This is how the young are taught about the realities of life and the complexities of existence. It is an education system without a recognised teacher, but which allows for the acquisition of attitudes and behaviours required of a good breeder. Within the scope of our research, basic knowledge concerning transhumance is taught: unless certain rules are respected, one’s own well-being will be compromised as will the economic and social development of the entire group. This is the inheritance which parents bequeath to their children.

### Table 6  Distribution of migrant breeders according to type and level of education

<table>
<thead>
<tr>
<th></th>
<th>Western school</th>
<th></th>
<th>Koranic school</th>
<th></th>
<th>Local apprenticeship</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Numbers</td>
<td>%</td>
<td>Numbers</td>
<td>%</td>
<td>Numbers</td>
<td>%</td>
</tr>
<tr>
<td>Owners</td>
<td>60</td>
<td>5.69</td>
<td>182</td>
<td>17.28</td>
<td>150</td>
<td>14.24</td>
</tr>
<tr>
<td>Herders</td>
<td>15</td>
<td>1.42</td>
<td>78</td>
<td>7.4</td>
<td>365</td>
<td>34.8</td>
</tr>
<tr>
<td>Helpers</td>
<td>0</td>
<td>0</td>
<td>37</td>
<td>3.51</td>
<td>166</td>
<td>15.76</td>
</tr>
<tr>
<td>Total</td>
<td>75</td>
<td>7.11</td>
<td>297</td>
<td>28.2</td>
<td>681</td>
<td>64.67</td>
</tr>
</tbody>
</table>

### A population without defence in the face of AIDS

Only a portion of the breeders who were questioned – 14.24% - had any idea of the causes, means of transmissions, symptoms, ways of prevention and possible treatment of AIDS. They had heard talk of the disease during some of the stays in towns and during stop-overs in transit sites during their treks. Of the 14.24% of the breeders who said that they knew of the existence of AIDS, half of this number – 7.12% – knew what caused it. A third of them – 4.74% – approximately fifty breeders could describe the symptoms of AIDS. The remainder had a vague and puerile general knowledge of the disease. 85.74% of the sample, that is to say 902 people, knew nothing about AIDS. By analysing each socio-professional group, it was possible to establish that the worst informed about the disease were the herders. This can be explained by their level of education which, as Table 7 shows, is very low especially where attendance at western type schools is concerned. As far as the owners are concerned, despite the fact that they had attended western or Koranic schools, with a 5.69% and 17.28%

respective level of education, their knowledge of the scourge was minimal – 5.31%. Consequently one could ask whether this disease was touched upon in places of learning or whether the respondents simply had not paid any attention when it was spoken of.

Table 7  Distribution of migrant breeders according to their knowledge of AIDS

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>%</th>
<th>No knowledge</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owners</td>
<td>56</td>
<td>5.31</td>
<td>336</td>
</tr>
<tr>
<td>Herders</td>
<td>65</td>
<td>6.17</td>
<td>393</td>
</tr>
<tr>
<td>Helpers</td>
<td>29</td>
<td>2.56</td>
<td>174</td>
</tr>
<tr>
<td>Total</td>
<td>150</td>
<td>14.24</td>
<td>903</td>
</tr>
</tbody>
</table>

The mobility of the breeders in the savannahs, the plains and the valleys does not allow them easy access to daily information. Their low level of education is another stumbling block. It must also be added that the region is not particularly well covered by radio waves. On the one hand, the region is too hilly which hampers good radio reception, television and the Internet reception; on the other hand, there is a shortage of electricity. The areas in which the breeders live and which they regularly visit have little access to this form of energy, thus restricting access to television and the Internet. Only 45.77% of those questioned had access to a means of information (Table 8). This percentage is even lower when applied to the possession and use of newspapers, radios and televisions during the transhumance period. Thus, only 19.18% of the breeders have access to information sources when they are on the move. Amongst these information sources, the radio is the most frequently used and the most accessible given its affordable purchase price and its ease of transport particularly in the case of small transistor sets.

Table 8  Access to information according to areas

<table>
<thead>
<tr>
<th>Departure areas</th>
<th>%</th>
<th>Transhumance areas</th>
<th>%</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radio</td>
<td>130</td>
<td>12.34</td>
<td>50</td>
<td>4.74</td>
</tr>
<tr>
<td>Television</td>
<td>2</td>
<td>0.18</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Newspapers</td>
<td>6</td>
<td>0.56</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Market</td>
<td>28</td>
<td>2.65</td>
<td>28</td>
<td>2.65</td>
</tr>
<tr>
<td>Associations</td>
<td>27</td>
<td>2.56</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Storytellers</td>
<td>35</td>
<td>3.32</td>
<td>51</td>
<td>4.84</td>
</tr>
<tr>
<td>Churches</td>
<td>49</td>
<td>4.65</td>
<td>73</td>
<td>6.93</td>
</tr>
<tr>
<td>Trad. authorities</td>
<td>3</td>
<td>0.28</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>280</td>
<td>26.59</td>
<td>202</td>
<td>19.18</td>
</tr>
</tbody>
</table>

Newspapers are foreign to the majority of those questioned who occasionally referred to writings summarising the Koran. Of the 1053 breeders interviewed, approximately 130, 12.34%, owned a radio in their native village but had not brought it with them. Two of the breeders (0.18%) owned a television set. About fifty of them (4.74%), many of whom were
Nigerian, Chadian or Cameroonian had a radio with them in their moving about. Our investigation showed that the frequency with which the owners of sets listened to the radio was relatively low.

The main reason for the low usage to information is poverty. The majority of paid breeders receive a wage which is too low to enable them to purchase a radio.

Table 9 shows that only 14.24% of the breeders have access to a means of communication providing information on HIV/AIDS. The breakdown per professional categories is as follows: owners (6.83%), herdsmen (3.79%) and family helpers (3.62%). This lack of access to information is due, according to some of the breeders, to the poor reception of the messages which are broadcast. Sometimes they are broadcast in a language which is foreign to the breeders and, in these instances, translation into a local language is not easy. In addition, the programmes and their schedules are not known in advance.

Table 9

<table>
<thead>
<tr>
<th>Access to information according to socio-professional categories</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>------------------</td>
</tr>
<tr>
<td>Radio</td>
</tr>
<tr>
<td>Télévision</td>
</tr>
<tr>
<td>Newspapers</td>
</tr>
<tr>
<td>Market</td>
</tr>
<tr>
<td>Associations</td>
</tr>
<tr>
<td>Storytellers</td>
</tr>
<tr>
<td>Churches</td>
</tr>
<tr>
<td>Traditional authorities</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
<tr>
<td><strong>Percentage</strong></td>
</tr>
</tbody>
</table>

Very few of the breeders have access to systems of modern health care, due to the distance between the transhumance places and the clinics. We estimate that the distance between the closest health care centre and Waza reserve to be ninety-two kilometres. In addition, the breeders do not like to be treated with modern medicine. Of the 1053 breeders who were questioned, 99, about 9.40%, said that they often went to hospitals when they were ill. These owners make use of modern medicine when they are in the villages. But they only go in cases of extreme urgency when all other attempts at cures have proved fruitless. During the period of our investigation, not a single breeder showed any wish to be treated in a hospital centre.

**Life styles favouring the spread of AIDS**

The difficulties which have been presented in the preceding paragraphs allow one to understand how the breeders contribute to the spread of HIV/AIDS in the region.

The shepherds, herdsmen and family helpers are to be seen as true migrants because they leave their normal homes for months on end for places which are foreign to them from every point of view. Social customs in the place of departure and the place of arrival can be very different. Careful observation of the shepherds’ lives shows attitudes which can contribute to the spread of HIV in both the places of arrival and return.
Depending on its orientation, the migration can have positive or negative effects. It is often encouraged by public authorities so as to readjust the population over the entire national territory and to avoid over population in the areas of departure. The migrants’ life styles are controlled and channelled in this way. In rural areas, for example, political authorities favour the newly arrived migrants by encouraging the redistribution of land and the absorption of the emigrants into a populace whose religion and customs they do not share. In such cases, the movement of the migrants is relatively well controlled. The immigrants participate in the improvement of agriculture in the arrival areas, the introduction of new marketing customs and new techniques of production.

This migration marks the countryside which it crosses by brutal changes in the plant cover and in heavy deforestation. The results on the environment as well as on the ecological and biological balance are equally important.

The migration caused by natural or artificial climatic changes result in a disorganisation of life styles. Most of the migrants’ relations remain in the departure areas or barely move away from them. Only the most able bodied, the breeders, move away. Their integration into a new geographic space favours the adoption of a different social life which distances itself from the customs in the areas of departure. The disordered family life in arrival areas impinges on traditional social life. Seen in this light, migration is a menace as it contributes to the weakening and decadence of traditional ways of social life. This menace is aggravated by the fact that the breeders are in the minority and are isolated in grazing areas. Uprooted during the period of transhumance, they no longer believe in the traditional values of their own society. Their isolation favours the practice of behaviours which increase the risk of the transmission of HIV.

Various cases which were noted during the investigation as well as field observations allow one to posit that the breeders are implicated in the spread of HIV/AIDS. Thus, during the periods of transhumance – on average two per year with an average duration of five or six months – the breeders find themselves in situations which favour the adoption of attitudes and behaviours which differ from those practised in areas of departure. Let us recall that the majority of the breeders are bachelors (57,64%) and, if we were to include widowers and divorcés, this percentage would rise to 81,38%. The majority of breeders – 97,7% – who move around are male. A considerable mass of individuals are therefore separated from their families. These migrants are deprived of the support of their families, which results in changes in their emotional and moral life as well as in their social habits. According to the information we have collected from the breeders themselves, this situation is difficult to endure.

During the long periods of absence associated with the transhumance, the breeders indulge in occasional sexual relationships. Many of them admit to having regular sexual relations with women whom they meet in the areas where they settle for a while. They are indeed isolated, in the middle of nowhere, and in foreign territory, far from their legal spouses or their girlfriends. We can say, after Lurie, that men who are far from their homes often have other partners in their work places. The migrants do not stay without women for long because the isolation in this new area allows them a greater sexual freedom than they would experience at home. They therefore indulge in unrestricted and unprotected sexual relationships. In fact, they do not know exactly from what they should protect themselves because most of them – 85,74% – do not know of the existence of HIV.

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1 The data on the breeders’ sexual activity are provided by the focus groups which were installed in the main transhumance areas in Adamaoa, Diamaré and Benoué during the months of March, April and May 2003 (see note 8, above). These investigations show that the breeders claim to be ignorant of the existence of AIDS (Table 7) and tend to adopt freer sexual behaviour patterns during their moving around.

2 Lurie et al., “Circular migration and sexual networking in rural KwaZulu-Natal” (see footnote 12).
The majority of the breeders questioned – 81.38% – move around without partners. Several studies have shown that the propensity to adopt at risk sexual behaviour is part of the condition of moving around. When one moves around with one’s girlfriend, wife or fiancée, at risk behaviour, seen as dishonourable, diminishes. The breeders who are on their own have greater sexual liberty. They are more likely to have multi-partners, thereby exposing themselves to HIV. This would explain the growth in HIV positive numbers in the Lake Chad basin since 1985. This increase can be explained, on the one hand, by the breeders’ ignorance of AIDS and, on the other hand, by the large number of young and single men amongst them. This ignorance results, in effect, in the adoption of at risk behaviour such as unprotected sexual relations and the use of dirty objects such as razor blades.

Two main centres attract the breeders during transhumance stay-overs: cattle markets and accommodating villages.

Cattle markets occur in precise places at precise times. They draw people from all directions, both urban and rural. Many small markets exist in the Lake Chad basin, filled with people of different origins. One of the most appreciated products is millet beer which is prepared at home and brought to the market, in calabashes, by the women. These markets are true cattle fairs. Everything can be found there: buyers, sellers, herder-drivers of the cattle who have come to town as well as loose women. For the breeders, the stay at the market is a holiday. Once their business has been concluded, they smoke, drink and look for girls, hoping to forget their separation from their families and the harshness of their pastoral life. Some of them go out with very young girls. According to one witness, several men will have sexual relations with the same girl. This behaviour takes place in all the cattle markets of the region, exponentially multiplying the risk of the spread of HIV/AIDS.

Among the markets, let us mention Banki, Kewara, Moubi and Soroa in Nigeria which are visited by breeders from Chad and Cameroon. Other examples are those at Bogo and Doumou in Maroua, Cameroon which attract breeders from southern Nigeria and other areas in Cameroon. A day spent at the Bogo market on the outskirts of Maroua allowed us to see that these markets are places for the significant exchange of money. Breeders sell cattle, others buy them. This is followed by festivities during which the breeders, fortified by alcohol, often indulge in sexual relationships.

Conclusion

The breeding sector has change little since 1985, the year when the first cases of HIV/AIDS were identified in the Lake Chad basin. It continues to be ruled by traditional techniques in pastoral matters. A population of breeders who are, for the most part, illiterate are constantly moving from one country to another. This unceasing migratory flow which are characterised by cattle and herders moving away from their normal habitat during dry and rainy seasons, results in the spread of various diseases including HIV/AIDS. This is what Henri Frechou observed when he noted that the presence of the Mbororo with their independent nature and continual migrations posed serious problems for administrative authorities. They saw the Mbororo as agents for the spread of contagious diseases from one country to another and forced them to submit to periodic vaccinations and to limit their migrations.1

Cattle breeders have, doubtless for a long time, been carriers of HIV. Nevertheless most of the programmes against AIDS ignore them. Few awareness campaigns have targeted them. This negligence has compromised the replenishment of the work force represented by young breeders. The pastoral sector is an important source for the creation of wealth and

1 Frechou, “The breeding and selling of cattle in north Cameroon” (see footnote 10).
development in rural areas. AIDS follows the geographic movement of the breeders who seek grazing during the dry season. It has not ceased to spread since 1985 in spite of national and transnational efforts on the part of health authorities.

(translated from the French by Carole Beckett)
Part Three

HIV/AIDS in the History of Epidemics
Historical Perspectives on HIV/AIDS
Lessons from South Africa and Senegal

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Introduction

The historical discourse surrounding the HIV/AIDS pandemic in Africa has been politically charged from its inception. Initially, some actors believed that the disease could be grasped exclusively in medical terms, and it took some time before the importance of cultural and social aspects was acknowledged. Closely associated with the politics of HIV/AIDS in South Africa have been the views of the President of South Africa Thabo Mbeki. His interventions in the scientific and political discourse on HIV/AIDS will be discussed in the conclusion to this paper. However misguided his position, Mbeki is by no means the first to grasp that epidemics are mirrors of society and its social tensions. To understand the social history of health in disease in South Africa, as in all other societies, it is impossible to separate the human body from the body politic.

While no one would leave out the politics of HIV/AIDS today, too often the scourge is viewed as a unique, unparalleled and incomprehensible catastrophe. While it is true in one sense that every disease, and every pandemic is different, historical precedents do exist both in the history of disease in South Africa, and elsewhere on the continent. Historians can contribute to the debate, and perhaps distil lessons from the exercise. In two insightful essays on this theme, Howard Phillips has illustrated both the continuities and the discontinuities represented by HIV/AIDS in South Africa. He also indicates in what sense the AIDS epidemic is unique, even if the response is not new. In this article, I draw on his examples and add my own from the social history of health and disease in Senegal.

South Africa

South Africa’s epidemiological record demonstrates how the politics of race have always been inextricably linked to public health issues. Sexually transmitted diseases (STDs) preceding HIV/AIDS have frequently spread with the accelerated migration of young male adults. Seamen, soldiers and migrant workers have often been inadvertent carriers in South

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Africa and in the wider world. But South Africa’s early and continuous practice of labour migration, together with the single-sex compound system of the mining economy, greatly facilitated the spread of syphilis (as well as respiratory ailments like tuberculosis). The system separated young black Africans from their wives for months or years, tolerated prostitution at the work sites, and then dispersed these labourers at the end of their contracts, often with these serious illnesses, back to their rural homes, where they unwittingly infected their loved ones.

Historical responses to infectious disease have followed a general pattern characterised by denial, blaming the victim, arbitrary use of state power, and criticism of allegedly negligent official authorities. Denial of the presence of the disease, or of its seriousness has occurred on several occasions. In the early 1880s Cecil Rhodes ordered his medical staff to dissimulate when a smallpox epidemic broke out among workers in the diamond fields around Kimberley. The illness they described they called “Kaffirpox”. A similar euphemism designed to protect business interests prompted some physicians during the bubonic plague outbreak in Cape Town in 1901 to label the disease as a benign fever. During the apartheid years, the government of South Africa refused to acknowledge serious cholera outbreaks in the Bantustans to avoid having to build costly water purification plants.

Stigmatisation and the blaming of victims has a long association with epidemic disease. The South African version early on developed a racial tone. In the nineteenth century, the linkage of the Enlightenment notion of “rational” control over a dangerous state of nature combined with western bio-medicine to transform Africans into living laboratory specimens. With the coming of bubonic plague to Cape Town and Port Elizabeth at the turn of the twentieth century, whites took discrimination one step further. Black Africans were uncivilised carriers of disease and needed to be separated from whites, a form of residential segregation which now dominated white discourse, and which Maynard Swanson famously labelled the “sanitation syndrome”. Bubonic plague and the politics of race and ethnicity helped diminish liberal resistance to discriminatory legislation in Cape Colony, and had implications bearing on the Constitutional Act of 1910, which established the South African Union on terms highly unfavorable to the interests of non-whites in the new federation.

For their part, some black Africans also saw disease in political terms, attributing the arrival in the 1890s of rinderpest, an imported cattle disease, as a deliberate white conspiracy to destroy African cattle and drive pastoralists into wage labour. A century later, some young African activists in Soweto satirically labelled AIDS “Afrikaner Invention to Deprive us of Sex”, a scare tactic to control personal behaviour.

The arbitrary use of state power under the guise of medical exigency is another common feature. At various times, the state imposed the following discriminatory measures: a complete ban on Indian immigration during the cholera scares of the 1890s; the forced removal of black Africans from central Cape Town and Port Elizabeth during the bubonic plague outbreaks of 1901; the “de-verminisation” of all black African train passengers during the typhus epidemics of the 1920s and 1930s.

Another infectious disease had an even more immediate impact on the political and social landscape of South Africa than did bubonic plague. The world influenza pandemic of

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1918 also contributed to the extension of discriminatory residential segregation laws.\textsuperscript{1} It led to the 1919 Public Health Act and the later recommendations of the Stallard Commission, which in turn formed the basis of the Native Urban Areas Act of 1923. The terrible demographics of HIV/AIDS and the loss of a generation of young mothers and fathers has its echo in the influenza pandemic. It cost South Africa, like virtually every other jurisdiction in the world, roughly ten percent of its prime workforce and created a missing cohort that worked its way through society for a generation. The economic and social costs of HIV/AIDS mortality threatens to be far more severe, of course.

Racist policies both reflected and shaped the course of chronic health problems such as tuberculosis and the diseases associated with malnutrition.\textsuperscript{2} Curative treatments pursued by the South African medical community did not succeed against a disease of poverty like tuberculosis because they failed to address the gross inequalities endured by black South Africans: a permanently transient labor force, overcrowded housing, inadequate sanitation, low wages, and poor health facilities. Similarly, South African nutrition scientists often inadvertently provided ideological support to white supremacists by denying, or not realising, that the political economy of mining was the real cause of South Africa’s food inequalities, leading to much malnutrition among black South Africans. Instead, even those scientists who were liberals were blinkered by their assumptions that Africans were incompetent farmers, and that African women were inadequate mothers and wives. In this vast exercise in blaming the victims, many in the white research community showed disrespect for local cultures, and dismissed Africans as an ignorant people without scientific knowledge.\textsuperscript{3}

**Senegal**

In colonial Senegal as elsewhere in Africa, epidemics and public health policy to combat them became part of the ideological contest between conqueror and conquered. Deeply embedded in French medical assumptions was a triumphalist Enlightenment rationality which empowered Western bio-medical science while contemptuously rejecting the applied knowledge of local healing specialists.\textsuperscript{4} Here again Africans were held to be a people without knowledge. Also rooted in the Enlightenment was the assumption that Western sanitary measures were humanitarian acts conferring moral legitimacy on their sometimes heavy-handed paternalist rule over “the other”.\textsuperscript{5} For many Senegalese, on the other hand, the bubonic plague outbreak was regarded as part of the colonial conquest, biological warfare in either symbolic or concrete form. European motives for attempting disease control were


\textsuperscript{4}Nancy Gallagher has argued that a similar power struggle occurred in Tunisia at the time of French conquest, when Arab medical specialists clashed with European practitioners of Western bio-medicine. See her Medicine and Power in Tunisia, 1780-1900 (Cambridge: Cambridge University Press, 1983).

\textsuperscript{5}Comaroff, “The Diseased Heart of Africa.”
questioned, and the measures often fiercely resisted, partly because they were highly intrusive yet ineffective, and partly because they were simply alien. Moving forward a century, the same belief in a conspiracy theory prompts some young Francophone Africans to call HIV/AIDS, whose acronym in French is SIDA, “Syndrome imaginaire pour décourager les amoureux” (an imaginary syndrome to discourage lovers). The parallel with South Africa here as well is striking.

The politics of public health in colonial Senegal have manifested themselves in the histories of yellow fever, bubonic plague, influenza, and STDs. Yellow fever was endemic, and most Senegalese survived their first encounters with the disease in childhood and acquired lifelong immunity. Not so for “unseasoned” fresh arrivals to the colony, most of whom were French. Once the vector was understood to be the *Aedes Egypti* mosquito, French health authorities embarked upon a vigorous campaign to eradicate the mosquito and its breeding sites in stagnant water. A major piece of legislation was the so-called “law of the three interdictions”, passed on 12 December 1912, prohibiting the collection of rainfall on roofs, in bottles on walls, or in ground-level containers. Yet drinking water, especially in Senegal’s northern towns, was always in short supply. Since health authorities did nothing to address the problem of an adequate supply of potable water, small wonder that the Senegalese population deeply resented legislation which addressed the health needs of the small French minority, and ignored Senegalese concerns.

In 1914, the third world pandemic of bubonic plague arrived in Senegal, not to withdraw for the next thirty years. French attitudes towards urban living in Senegal at that time were no different from those of Europeans elsewhere on the African continent. Precedents and policy for separating Senegalese from Europeans in the towns and cities of Senegal go back at least to the foundation of Dakar in 1857. Here too the “sanitation syndrome” was at work. Virtually the entire French medical community agreed that Senegalese should live separately from the French, and used the Dakar bubonic plague outbreak of 1914 as a paradigmatic case. Private and public French voices not only blamed the Senegalese victims of this scourge, they sought to exploit the epidemic to intensify their control over African property and lives in Dakar. The most glaring example was the creation of the Médina as a segregated village removed from the central plateau area dominated by French businesses and residences.

To combat the plague, health authorities authorised highly intrusive and coercive measures. Although quarantines and *cordons sanitaires* were ineffective against biting insect-borne diseases, officials insisted on these practices, which caused food shortages in outlying villages and added to the death toll. Control of cultural space was violated by the denial of Muslim and other ritual burials in favour of mass burials in lime. Health officers burned the property of Senegalese while sparing unsanitary French buildings. They made anti-plague vaccination compulsory for Senegalese, and optional for French, even though the inoculation offered only limited protection and brought with it harsh side effects. As in South Africa, the Senegalese population responded with resistance ranging from failure to report cases and clandestine burial to harassment of health agents, strikes, boycotts, and street demonstrations. Some even went so far as to interpret bubonic plague, or the vaccination campaigns, as an attempt of the French to wage biological warfare on the Senegalese majority. Most

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importantly, and in contrast to South Africa, a small, politically aware Senegalese elite used legal means to resist arbitrary treatment. Blaise Diagne and the Senegalese évolués successfully opposed discrimination masking as health policy. Residential segregation in the Dakar Médina failed, and Senegalese, mostly assimilated but some not, continued to live in the city centre.

The world influenza pandemic struck Senegal in the fall of 1918 and affected work in fields following the rainy season. Schools and clinics were closed, and the colonial administration virtually ceased to function in most regions of the country for six weeks. Upon its retreat, flu left roughly 47,000 dead among population slightly over 1 million, making it the worst single medical calamity in modern Senegalese history. As was the case the world over, health authorities lamely sought to control flu’s spread and to cure its victims. Nevertheless, the chief of the Health Service, Dr. Thoulon, believed in alcohol as a stimulant and prescribed this, even for Muslim patients. Its compulsory administration to Senegalese soldiers caused great offense to their families and to Muslim religious authorities.

No full study of the earlier history of STDs in Senegal yet exists. An overview by Charles Becker and René Collignon suggests a pattern common to the experience of South Africans. French colonial public health officials were too quick to blame Senegalese, and to assume a high prevalence of STDs without sound evidence. Social Darwinist assumptions too often led health authorities to predict degeneration of the population. Rather than recognising stoicism in the face of scourges which could not be easily recognised or treated, French health officials castigated the Senegalese for their indifference to chronic gonorrhoea and symptoms of primary syphilis, or for their allegedly “excessive copulation”.

Yet colonial health authorities did take one step which would bear fruit later. They imposed controls on sex workers, obliging them to submit to medical inspection and licencing periodically. The arrival of antibiotic injections in the 1950s created a revolution in treatment, and by the time of independence, the capital region of Dakar had some control over STDs, an issue of some importance when the country would encounter HIV/AIDS.

Despite historical similarities with South Africa in its colonial public health history, Senegal’s recent experience differs greatly in one dramatic sense, its encounter with HIV/AIDS. As John Iliffe notes in his excellent new history of the HIV/AIDS pandemic in Africa, Senegal "was arguably the only country in sub-Saharan Africa to prevent a generalised HIV/AIDS epidemic, its adult prevalence never rising much above 1 per cent." Drawing on Green, and especially N. Meda et al, Iliffe offers a series of explanations for Senegal’s good fortune.

First, the initial infection to strike Senegal was the less virulent HIV-2 form. The first HIV-1 case was not observed until 1986. HIV-2 was endemic among sex workers in Dakar and especially in southern Casamance, bordering on the epicentre of the disease in Guinea-Bissau. The first HIV-1 cases were mainly foreigners or Senegalese men who had travelled

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HIV/AIDS in the History of Epidemics

elsewhere in West or Equatorial Africa and who frequently had histories of homosexuality and drug use.

The second factor was cultural, having to do with conservative Muslim values. Senegal’s overwhelmingly Muslim population everywhere except the Casamance experienced a late median age for sexual debut, at roughly 19 years for both sexes in the late 1990’s. Non-marital sex rates were low outside the capital of Dakar, and condoms were widely used with casual partners. Muslim leaders cooperated with the country’s Aids Control Program, launched as early as 1988, and discussed the disease and behaviour in their Friday sermons. Unlike many Christian churches elsewhere in Africa, Islam had a tradition of leaving moral judgments to God and of rejecting stigmatization for those who were HIV positive.

Third, the Government took an enlightened approach to the disease from the outset. President Abdou Diouf was proactive, and quick to allow the Senegalese medical community to intervene, whether to control the blood supply, to use public education, or to accept assistance from international non-governmental organizations.

Lastly, Senegal’s historical public health experience contributed to success. Under French rule, the licensing and inspection of sex workers had constituted a mechanism of for control of STDs which was not found in former British territories in Africa. In post-colonial Senegal, health authorities not only expanded the number of health clinics treating STDs from Dakar to other towns, they established a medical culture in which people were encouraged to seek biomedical treatment for STD infections.

Conclusion

No discussion of HIV/AIDS in South Africa past or present can avoid the controversy pitting President Thabo Mbeki against the international scientific community and the pharmaceutical companies. Several writers have addressed Mbeki’s position on AIDS. Mbeki has been stung by the assumptions about African inferiority and sexual promiscuity buried within conventional AIDS wisdom. His experience as a black South African has taught him that labels of inferiority ultimately translate into arguments and policies reinforcing subordination. Arguing that the pace of AIDS infection has been different in Africa than in West, he believes it requires an African response to the problem. In Africa, the disease has attacked heterosexuals, has attained a much higher death rate, and the figures continue to rise in epidemic proportions.

Yet Mbeki has also gone further. Although he has claimed not to endorse dissident theory, and purports to keep an open mind, he has defended these dissidents against what he feels have been vicious attacks reminiscent of the apartheid days. He has also resented the neo-colonial tone of many scientists who have often spoken as if the only freedom of Africans “was to consent to truths they decreed in their scientific establishments.” Finally, Mbeki

4 See Mbeki’s open letter to President Clinton and to Secretary-General Annan, in the Sunday Times (South Africa), 23 April 2000. Full text at www.virusmyth.com.
continues, the HIV/AIDS issue has perpetuated the negative image of Africa as a sick continent, and has led to “Afro-pessimism”, the belief that there is no hope for the future. Well before the AIDS controversy sprang up, Mbeki had been a proud articulator of the “African Renaissance”, as a means of having Africans rediscover and affirm their cultural identity.1

Although sincerely felt, Mbeki’s rigid and reductionist opinions have done considerable damage to the struggle against HIV/AIDS in South Africa.2 He has failed to realise that while medical epidemics are constructed, they also kill people. Two remarkable figures with a political history similar to Mbeki’s, Nelson Mandela and Zackie Achmat, have understood this well. As Mandela has often said, “HIV/AIDS is a war on humanity”. Mandela’s moral intervention and Achmat’s activism have done much to bring about a change in the South African government’s position.

Mandela’s tremendous prestige and his impressive skills at mediation became evident during the Eleventh World Congress on HIV/AIDS, which met in Durban in July, 2000. For the first time, extensive discussion took place around the hitherto neglected social, economic, cultural and political dimensions of the pandemic. While Mbeki remained intransigent, and continued his attack on what he called the “grossly unethical” behaviour of the giant pharmaceutical companies, Mandela put his mediator’s skills to work at Durban:

I do not know enough about science or the politics of science to even start to contribute to the debate raging around the periphery of this conference. But in all disputes, a point is arrived at where no party – no matter how right or wrong – will any longer be totally right or totally wrong.3

Mandela had grown troubled by the misunderstandings Mbeki’s objections might produce. By denying the seriousness of HIV/AIDS or by reading it as a western conspiracy, Mbeki allowed young South Africans to believe that they did not have to modify their sexual behaviour. Especially worried about mother-to-child transmission, Mandela was anxious to see the South African government endorse the use of the anti-retroviral (ARV) drug, Nevirapine. Mandela’s speech at Durban called on South Africa to join with Uganda, Senegal, and Thailand in mounting concerted action to combat mother-to-child transmission, pursue vaccines, and end stigmatisation and discrimination of victims.

Meanwhile, an HIV-positive South African named Zackie Achmat was making a name for himself and the movement he founded, the Treatment Action Campaign (TAC).4 Ironically, Achmat shared with Mbeki a history of activism and militant resistance to apartheid, but their diverging personal experiences had carried them down very different paths. While Mbeki, a senior figure in the African National Congress, was hand-picked by Nelson Mandela to succeed as head of the African National Congress and president of South Africa, Achmat was organising fellow HIV-positive South Africans to oppose the negative position of Mbeki and his government towards ARVs.

Achmat shared some of Mbeki’s assumptions but reached very different conclusions. He recognised that the AIDS discourse presenting a sick and promiscuous African had deep colonial roots, and he also resented Afro-pessimism as the latest discourse of African inferiority. He also expressed anger at the greed of the pharmaceutical companies. But unlike Mbeki, Achmat recognised the value of the ARVs, and pushed hard to alter pricing policies

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1See Thabo Mbeki “I am an African”, statement made on the occasion of the adoption of the Constitutional Bill by the Constitutional Assembly, Cape Town, 8 May 1996, reprinted in Thabo Mbeki, Africa. The Time has Come. Selected Speeches by Thabo Mbeki (Cape Town: Tafelberg, 1998).
3The full text of his address can be found in “Nelson Mandela on Treatment Access”, October, 2003; <http://www.thebody.com/atn/393/mandela.html>.
while also urging Mbeki to change his position. Using tactics of the anti-apartheid years such as street demonstrations and civil disobedience, the TAC kept up pressure for a change in public health policy. Achmat and the TAC mobilised 5,000 people wearing HIV-positive t-shirts into the streets at the Durban Conference in 2000.

Achmat and the TAC put forward a wise suggestion that researchers needed to focus on co-factors in HIV/AIDS, rather than on blaming victims for their risky behaviour. Attention needed also to be paid to structural inequalities which caused patients to die from a treatable disease because they were poor. Achmat had grasped the lesson of history which had escaped Mbeki; that criticism of the old politics of health and disease should not lead to the rejection of such demonstrably useful products of western bio-medicine as ARVs which had transformed HIV/AIDS into a chronic rather than a life-taking disease.

After Mandela and Achmat had taken the stage at Durban in 2000, in the fall of that year Mbeki reluctantly gave ground. Since 2001, he has remained relatively silent on the AIDS issue, probably as a result of pressure from the trade unions and the business sector. His government has also allowed Nevirapine to be administered to pregnant HIV-positive women in KwaZulu-Natal. The victory not only promised to save thousands of lives in South Africa. It also demonstrated the power of civil society in a democracy to create positive change.

The history of how societies have responded in the past to pandemic disease offers a simple but important lesson in public health policy. The experiences of colonial Senegal and of South Africa would suggest that health policies and programs imposed from above which do not respect subaltern voices are doomed to face strenuous resistance and likely failure. Senegal’s post-colonial history, however, offers a more positive lesson. It shows that health policies attuned to the local medical, cultural and social environment are much more likely to succeed.
Historicizing the Unspeakable:
Legacies of Bad Death and Dangerous Sexuality in South Africa

**Benedict Carton**

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UNokufa

Whenever I tried to visualize you, Death, …
I thought I saw you lurking in the darkness, …

Then you appeared, and families were scattered
And many alas, were lost to us forever! …

Again I cry, alas! For have I not seen
The children of Sihlonono
Dying in their prime?

Have I not watched, behind a screen of shrubs,
The daughters of our scattered tribes
Abandon the struggle to keep their maidenhood
And quench the lust of youths who were their kindred.


It has become a sad truism that black youths comprise one of the most vulnerable “risk groups” in South Africa. Their rising rate of HIV infection is ascribed, in part, to chronic unemployment, which afflicts post-apartheid society and frustrates their “pursuit of modernity.” In this milieu transactional sex becomes a vital source of income and commodities.2 Such quests, in turn, stoke rumours that fertile women with multiple partners proliferate *ukufa* (“bad death” in Zulu) in provinces hit hard by AIDS like KwaZulu-Natal. This charge of promiscuity embodies a prominent concept in Zulu cosmology, dread of *umnyama*, “pollution” that can be transferred sexually. It also evokes a hackneyed colonial idea that African sexuality is debased and menacing. More than anything, the latter accusation triggers conspiracy theories that blame whites for hatching AIDS and injecting it into blacks.3 Some observers of the pandemic have asserted that these attributions reflect


A revered Zulu intellectual, Vilakazi grew up in colonial Natal learning the dramaturgies of “Africa of old.” A decade before his birth in 1906, his parents lived through the rinderpest epizootic that swept through eastern and southern Africa. By 1897, this virulent bovine virus had left the “velt strewn in carcasses and the cattle kraals emptied of every ox, cow or calf their owner possessed.”\footnote{Minute (Min.) Paper (P.) Secretary for Native Affairs (SNA), 21 Aug. 1897, 1645/1897, 1/1/252, 1/SNA, Pietermaritzburg Archives Repository (PAR), KwaZulu-Natal, South Africa. Vilakazi and “Africa of old”: B. Peterson, \textit{Monarchs, Missionaries \& African Intellectuals} (Trenton, NJ, Africa World Press, 2000), Chps. 3-8.} Four decades later, B. B. W. Vilakazi helped compile a massive \textit{Zulu-English Dictionary} that classified thousands of terms, among them (bad) “death” and “rinderpest.” The suffix \textit{fa} (die) is followed by many definitions, alluding to plague, unseemly craving, diseased cattle, and “one vicious person [who] will infect a whole community.” One term for rinderpest, \textit{umaqimulana}, describes how livestock perished “like flies,” an apocalyptic vision summarized in \textit{ukufa} idiom, \textit{zabulawa ngukufa zathi qimu}: “They were destroyed by epidemic, collapsing everywhere.”\footnote{Definitions of \textit{fa}: 197; rinderpest: 707; in C. M. Doke and B. W. Vilakazi, compilers, \textit{Zulu-English Dictionary}, 2nd Edition (Johannesburg, Witwatersrand University Press, 1953), republished in C. M. Doke et al. compilers, \textit{English Zulu, Zulu English Dictionary} (Johannesburg, Witwatersrand University Press, 1990). The “Introduction” (xii) in the \textit{Zulu-English Dictionary} (1953) applauds the etymological contributions of Dr. B. W. Vilakazi.} Vilakazi’s etymologies confirm that notions of epochal misfortune and \textit{ukufa} had already been enfolded into the Zulu language.

The similarities between AIDS and rinderpest extend beyond linguistics. Both outbreaks evolved from epi- to pan-phenomena, prompting the urgent attention of Western medical scientists.\footnote{Epi- to pan-phenomenon, biomedical intervention, and Western attitudes regarding cattle disease and AIDS: J. Fisher, “Cattle Plagues Past and Present: The Mystery of Mad Cow Disease,” \textit{Journal of Contemporary History} 33, 2 (1998), 224, 215-167, 221.} They also highlighted the unremitting pressures on African families and restlessness of their youths. The epizootic, which originally leaped from Europe into Africa in the late nineteenth century, eradicated a prized source of exchange upholding customs regulating fertility. In the absence of bridewealth cattle that sealed nuptial negotiations sanctioning reproduction, Zulu-speaking youths at the turn of the twentieth century increasingly engaged in premarital intercourse. Such transgressions alarmed elders who safeguarded sexual norms to buoy their sinking world of domestic patriarchy. After the British conquest of Zululand in 1879, white authorities imposed heavier taxes on homesteads and appropriated more land from chiefdoms. Shrinking “native reserves” yielded fewer crops, which propelled youths to seek wages in the colonial economy. Their income helped to pay taxes and purchase family provisions; it also shifted their expectations.\footnote{J. Lambert, \textit{Betrayed Trust: Africans and the State in Colonial Natal} (Pietermaritzburg, University of Natal Press, 1995), Chps. 3-8.}
When the abasha ("new or modern ones") searched for better prospects, they exercised greater social autonomy, which apparently led to a rise in premarital "seduction (making pregnant)." At the centre of this era’s "loose morality" tales were izinkhanuka, so-called wayward children, but particularly young women, some of whom became prostitutes infected with isimpantsolo, gonorrhea. Forbidden sex, a source of hazardous bodily pollution, now coincided with strong umnyama conveyed by a killer disease, rinderpest, which colonists allegedly battled but appeared to abet. This confluence of circumstances haunted and inspired Vilakazi. While he bemoaned the dangerous symbiosis between unfettered sexuality and tragic mortality, he also sought regeneration. Zulu nationalism, Vilakazi claimed, could revitalize a depleted people, halting the rampages of Western civilization that "delimit[ed] the social powers" of their kings and upset the moral compass of their "Nation." In this sense he envisaged colonial modernity as a sexually transmitted disease, dissipating black victims in their prime, whether “daughters of our scattered tribes” or migrants “exploited in the mines.”

Vilakazi’s Zulu-speaking cohorts similarly indicted injurious white rule. In a 1927 speech African National Congress (ANC) President Josiah Gumede denounced the “hopeless suppression” of Zulus yoked into industrial compounds, which incubated tuberculosis and silicosis. “What exploitation!” he declared, made possible by “diseases . . . introduced into South Africa which wiped out our cattle. We think this was done deliberately to force us to go down the mines.” He confirmed his suspicions three decades ago in Natal, when he witnessed “misfortune maliciously” delivered. In 1897 he petitioned the Natal government to stop “any European who may try and advise us in our difficulties.” Citing “our downfall and the dead” herds, Gumede decried the “brutal dominering treatment” of colonial “rinderpest commissioners.” In the months following his letter, with the bovine virus running amok, whites injected vaccines in African cattle that spread, rather than arrested, ukufa.

With such evocative evidence available, it is surprising that “reams of writing on AIDS in South Africa” have portrayed the pandemic as black people’s unprecedented and inscrutable tragedy. This perception, University of Cape Town historian Howard Phillips argues, rests on shallow memory. To be sure, his profession bears some responsibility for its failure to place catastrophic outbreaks in the “mainstream narrative of the country’s history.” AIDS could be better comprehended, he suggests, if “set comparatively against” previous “epidemic experiences.” This recommendation, I argue, should encompass plagues that leveled animals vital to human prosperity, reproduction, and cosmology. This chapter extends recent inquiries into the roots of sexual and etiological socialization underlying

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5 Petition by W. Gumede et al. to Government of Natal (Josiah Gumede admitted that he wrote this petition), Min. P. SNA, 29 Nov. 1897, 2704/1897, 1/1/267; background evidence: Min. P. SNA, 5 Aug. 1897, 1487/1897, 1/1/250; Min. P. SNA 10 Aug. 1897, 1642/1897, 1/1/252; 1/SNA, PAR.
“humanity’s deadliest cataclysm.”¹ To this end, I begin with topical debates that inform historians’ understanding of the unfolding pandemic, and introduce a neglected “ways of death” scholarship that could offer compelling insights. The narrative then examines mounting fears of untimely death and contaminating sexuality during rinderpest and AIDS. These two episodes of crisis mortality, triggered by the decimation of multitudes, spawned similar recriminations against perceived guilty parties. Such scapegoating reflected disempowering gender and racial dynamics, which at times dovetailed with ambivalent attitudes toward biomedical intervention.

The analysis of rinderpest primarily depends on archival sources. The section on AIDS is more ethnographic and exploratory in scope, using oral testimony I collected in South Africa from July 2002 to August 2003 and February 2004 to July 2004, with Zulu-speaking informants residing in the Midlands-Pietermaritzburg region, Thukela valley, and metropolitan Durban of KwaZulu-Natal province. In preparing for these face-to-face discussions, I re-examined field notes recorded in the early 1990s, when I conducted doctoral fieldwork. Ten years ago, I investigated power struggles in traditional Zulu communities enveloped by civil conflict. This testimony and some of the same informants clarified gender and generational perspectives of mortality and sexuality.²

From Taboo to Topic

In the 1980s, as AIDS gripped the Sub-Saharan region, historians of South Africa expressed growing interest in biomedicine. Over the next decade, they examined past epidemics and health policies, but difficult questions soon arose about expanding this line of inquiry to investigate the current pandemic.³ How could an oral historian, for example, study a scourge that stigmatizes gravely ill patients and silences their survivors? If a researcher could interview people with AIDS, could she broach the taboo subject of risky sex?⁴ Such investigations invariably evoked a racial myth cultivated by European rulers in Africa, who claimed the Dark Continent writhed with reckless breeding and random dying.⁵ Indeed, this indictment hovered over HIV-prevention efforts aligning race and sexuality on an axis of grim mortality.

However, two events encouraged historians to cross the minefield of blame and shame. The first was the formation of a Truth and Reconciliation Commission (TRC) shortly

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⁵ M. Mchunu, “Zulu Fathers and their Sons: Sexual Taboos, Respect and their Relationship to the HIV/AIDS Pandemic”, unpublished paper, University of KwaZulu-Natal, 2005, 14; this study is part of Mchunu’s MA thesis on “Zulu masculinities.” I thank Macingwane for his scholarship.
after the 1994 historic ballot ushered the ANC into power. Despite controversial amnesties and confessions, the TRC managed a post-mortem examination of human rights abuses committed between 1960 and the advent of democracy. While the TRC fostered restorative justice, revelations of twisted science came to light. White scientists in Roodeplaat Laboratory, for example, testified that they endeavored to manufacture drugs to destroy black fertility. Apartheid contraception campaigns had already reduced African birth rates; the Roodeplaat experiments merely amplified whispers that white supremacists deviously aimed to extinguish the majority. The TRC disclosures and national debates they kindled converged in compelling ways to engage historians, some of whom started to reconsider the interlocking legacies of racial injustice and medical science.

This historiographical turn accelerated with global efforts to combat HIV. In the late 1990s health NGOs placed South Africa near the top of their urgent intervention list. They posted bulletins in provinces with high infection rates admonishing individuals to avoid unsafe intercourse. Informed by “western-derived theories of . . . rational decision-making,” these messages sought to initiate behaviour change. In effect well-meaning “safe-sex” approaches overlooked crucial collective factors, i.e., the unequal gender relationships driving a “sugar daddy” phenomenon that lengthens the devastating reach of HIV. Moreover, contrary to TRC hearings that explicitly promoted conciliation between perpetrator and victim, safe-sex campaigns preaching personal responsibility could spur rage and alienation. Outside Durban in 1998, an advocate of AIDS awareness, Gugu Dlamini, who had announced her HIV-positive status, was beaten by a crowd and died of her injuries. In KwaZulu-Natal youths were said to be expressing what anthropologist Suzanne Leclerc-Madlala chillingly called “infect one, infect all” fatalism. The country’s attention was shifting from the subject of nation-building to public health.

In the new millennium several academic initiatives revealed just how significant this shift was. In a milestone 2001 “AIDS in Context” international conference at the University of the Witwatersrand, historians joined scholars from other disciplines to discuss a perspective “largely unrepresented” in biomedical approaches to the pandemic, the social factors fuelling the spread of HIV/AIDS. A raft of presentations appeared in a 2001 South African Historical Journal edited by the historian Alan Jeeves. Additional conference papers became part of a special 2002 volume of African Studies. A central article in this issue, a two-century survey of “sexual socialisation in South Africa,” posed a crucial question: Why are black youths so susceptible to contracting HIV? The authors, historians Peter Delius and Clive Glaser, skillfully answered by tracing how Victorian Christianity and rapid urbanization

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obstructed channels of communication on sexual issues within peer groups as well as between parents and children.\(^1\)

The groundbreaking scholarship of Delius and Glaser could be extended to encompass bereavement customs that restricted intimacy.\(^2\) To this end, scholars could consult a “ways of death” school that has yet to influence South African historiography. The “ways of death” oeuvre came of age in the 1970s, drawing on Phillippe Ariès’s analysis of Western eschatology from the Middle Ages to the last century, including funereal rites that distinguished between tainted and accepted mortality.\(^3\) Ariès’s research spanned vast gaps in time, which subsequent historians filled. David Stannard, for one, adopted strands of Ariès’s framework, but concentrated on death anxiety in early New England. Stannard pinpointed two major factors in the “Puritan way of death,” the soaring mortality rates of English children and Christian rites that exalted in the salvation of devout elders. These determinants impelled fathers to withhold parental love, fearing that this affection would sap their children already weakened by Original Sin and the harsh New World environment.\(^4\) The entwined relationship between patriarchal obligations, avoidance practices, and malignant pollution is not unique to the Puritans. Indeed, this interplay profoundly affected the ways in which Zulu-speaking Africans dealt with ruinous pestilence.

“Does this cattle disease come from the brown people only?”

In 1896 rinderpest raced into South Africa, arriving in Natal and Zululand on the heels of disastrous droughts and locust swarms.\(^5\) The bovine virus gutted herds fitfully recovering from searing heat and meager grazing; high fevers knocked them senseless; lesions clogged their insides; and diarrhea drained them of fluids. Death came in a fortnight to hundreds of thousands of cattle. Yet livestock were not the only victims of rinderpest. Mission doctor James McCord, whose “patients were Zulus,” recorded how “the wiping out of all but one per cent of their cattle deprived them of milk and meat.” Some children “showed the effects of a deficiency diet,” he observed, in “incipient tuberculosis, digestive troubles, . . . and acute fever resulting from lowered resistance.”\(^6\) During this misfortune, Zulu-speaking people, particularly patriarchs responsible for the health of their homestead, implored the ancestors, \textit{amadlozi}, not to forsake them.\(^7\) Spiritual intervention involved penitential rituals, \textit{ukuzila}, entailing the withdrawal from normal routines. \textit{Ukuzila} overlapped with \textit{ukuhlonipha} customs regulating deferential marital and sexual interactions in accordance with patriarchal prerogatives. A trio of Zulu-speaking homestead heads in 1900 described “\textit{zila-ing},” which contained the \textit{umnyama} potent in women of childbearing age: “[W]hen a woman is

\(^1\) Delius and Glaser (2002).
\(^3\) P. Aries, \textit{The Hour of Our Death}, translated by H. Weaver, (New York: Knopf, 1981); this book drew on themes he developed in \textit{Western Attitudes Toward Death: From the Middle Ages to the Present}, translated by P. Ranum, (Baltimore: Johns Hopkins University Press, 1974).
menstruating she will not for seven days sit on her husband’s mat, nor will she take a pinch of snuff . . . [and] when men have been called out to fight [husbands will] not cohabit with their wives.”

With herds vanishing, however, male elders struggled to reinforce sacred *ukuzila* rites. For example, they found it difficult to call out sacred praises to *amadlozi* in crucial ceremonies (“the bringing back”) that banished *ebumnayameni*, malevolent pollution. In the early twentieth century Ntshelele, a Zulu traditionalist, recalled how cattle propitiations enabled the “person who is calling out the praises” to proclaim “‘Here is the beast with which we are bringing you back’ . . . . ‘Let us leave off living in blackness (ebumnayameni) . . . .’”

In the wake of rinderpest, the patriarch Mkando remarked that since he had “no cattle to kill,” he did not “see amadhlodzi” and could not say “where they have gone.” He knew, however, that “they left us with death,” for “[e]ven young people die off. The least thing kills them.”

In addition to their diminished constitution, African youths suffered other disabilities. The sudden loss of cattle undermined the bridewealth negotiations of sons and daughters, who hoped to gain in standing as married, child-producing adults. Youths who obeyed *ukuzila* and *ukuhlonipha* believed their fealty would be rewarded. A homestead patriarch, for his part, granted loyal sons permission to offer bridewealth cattle, *ilobolo*, and take a wife. However, “there was no cattle left for lobola,” chiefs Mabizela and Bande explained, and alternative nuptial gifts like cash failed to win wide endorsement.

The corollary of “no cattle for lobola” meant some youths ignored norms of non-penetrative premarital sex, *ukuhlobonga*, and proceeded to full intercourse. In keeping with the customary censure of assertive girls, a Zulu traditionalist named Qalizwe blamed female *izinkhanuka* for “allow[ing] their lovers to penetrate.” Calling this “amount of seduction . . . abnormal,” a group of Zulu-speaking male elders vented their misgivings. One of them, Ndukwanana, lamented that “girls have defied their parents; formerly when admonished about their behaviour, they were obedient.”

Some daughters were even said to be imbibing “unheard of drugs,” which made them bellow and act impulsively. Their troubled state, the patriarch Majumba said, provoked boys “who had fallen in love . . . to break off their

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4 Testimony of Ndukwana, 17 Aug. 1902, *JSJ*, 287-89, 318; statement of Mabizela and Bande, Min. P. Magistrate (Mag.) Klip River to SNA, 23 Oct. 1897, 2375/1897, 1/1/254; collapse of *ilobolo*: Min. P. SNA 28 Sept. 1897, 2101/1897; Min. P. SNA 17 Nov. 1897, 2590/1897; *ilobolo* of “equivalent value”: Min. AG, 10 Dec. 1897; Circular (USNA) for SNA, 17 Dec. 1897; Min. P. SNA, 10 Dec. 1897, 2858/1897, 1/1/268; 1/SNA PAR.

5 Neither homestead heads nor colonial authorities believed they could prevent premarital sex, especially when daughters “deserted their parents to join their intended husbands”: Statement of Mabizela and Bande, Min. P. Mag. Klip River to SNA, 23 Oct. 1897, 2375/1897, 1/1/254, 1/SNA. *Ukuhlobonga* leading to intercourse: Testimony of Mgqayi (relayed by Qalizwe), 22 June 1899, 247, in *James Stuart Archive*, 5 (2001); B. Carton, *Blood from Your Children: The Colonial Origins of Generational Conflict in South Africa* (Charlottesville, University of Virginia Press, 2000), Chp. 3.

engagements,” indicating perhaps that young women could have parried unwelcome advances with peculiar behaviour in order to court a more alluring suitor. At this time single sons saved earnings from labour migrancy to purchase concertinas, which they played to woo girls “in the dark.”

Zulu critics of izinkhanuka denounced the lure and illness of urbanization. One Zulu-speaking delegation singled out African town women as “the treacle [raw sugar] which draws our young men like flies.” Qalizwe condemned girls who “bunguka (become deserters) from home.” They embraced prostitution and contracted “’isimpantsolo’ [gonorrhea],” which made them “feel … that they are people of no worth (abase Bantu ba luto).” The incidence of gonorrhea likely stoked anxieties over the build up of pollution-induced disease. Indeed, as white rule and ecological crises converged, umnyama appeared to thrive. The Zulu informants in anthropologist Harriet Ngubane’s study of unusual misfortune and death as well as the flouting of “correct behaviour (ukuzila)” described what happened to a woman if she violated sexual propriety when pollution attained “epidemic proportions.” If she did not remove herself from society, Ngubane relays, she could become “a sexual pervert, speak or sing when she should not, and be aggressive without any provocation.”

Like African patriarchs, government authorities registered alarm over “loose morality.” The threat of so-called idle primitives lapsing further into degeneracy consumed Natal politicians and their white constituents. It also appeared to motivate a conference on rinderpest convened by representatives of the four colonial South African territories in 1896. Early in the proceedings, they railed against the “ignorant kraal native” and his “straying” livestock. This clamour heralded a familiar purpose: To segregate decadent others (“indigenous to the Dark Continent”) who allegedly imperiled the “civilization of Europe.” Colonists predicted ruin if wandering “natives introducing the disease” were not “check[ed],” a contention that Natal settlers “in a position to see the ravages” repeated when portraying Africans as “too lazy to move themselves in the matter.” To create a single infectious menace, native affairs officials, if not government veterinarians themselves, blurred distinctions between cattle and their African owners.

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Soon after the conference, Natal authorities refurbished measures deployed during smallpox to fight rinderpest. The late-1890s cattle regulations included enforced isolation and mandatory “disinfecting,” not only of herds but also of Africans. The District Surgeon’s contagious disease guidelines were rephrased and issued to Veterinary Surgeons and their colleagues, principally magistrates and policemen.1 They fanned out to corral Zulu ox-wagon drivers, who were quarantined for up to seven weeks, sometimes without sufficient food.2 Duly appointed “rinderpest commissioners” arranged for “kraal natives,” deemed at risk of transmitting the contagion, to be doused in antiseptic. Border guards oversaw fumigation at railway stations, where African passengers were stripped before being drenched in chemicals.3 In pass offices, barrels were converted into bathing vessels containing “Perfect Purifier,” about which archival documents disclose little. One white pass inspector in 1897 noted how “Native (Males) are required to wash, . . . [while] Native (Females) are . . . required to wash their feet and legs to the knees and their hands, and arms, also passing their hands over their hair.”4

When they could Africans openly objected to this treatment. A man known as Goba wrote the Native Affairs Department, inquiring why he was “troubled to this extent by being compelled to wash in evil-smelling preparations . . . ?” He recounted an exchange with border officers that began with his query: “‘Do the white people wash also?’ They said ‘They do not.’ ‘I asked why not?’ They said ‘Because you are a native, you were born here.’” Goba then issued a challenge: “‘I see that the white people and the brown people live mingled together, why do you select the brown only? [D]oes this cattle disease come from the brown people only?’”5 Goba and other African men demanded a stop to their abuse. Their appeals were not without prior cause. Arbitrary dousing stirred memories of another dragnet three years earlier, when inhabitants of “kraals” suspected of harboring smallpox had to go “naked

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3 Letter, Superintendent Native Locations to Mag. Indwedwe, 14 Sept. 1897; Min. P. SNA, 15 July 1897, 1310/1897, 1/1/249; Letter W. Mtembu to SNA 7 Jan. 1897; Min. P. SNA, 7 Jan. 1897, 37/1897, 1/1/236 1/SNA, PAR. Border guards served the Native Affairs Department and Minister of Agriculture.

4 Letter, Superintendent Border Guard, District 34, Umntawuma Drift, 20 July 1897, Min. P. SNA, 8 July 1897, SNA 1233/1897, 1/1/249, 1/SNA, PAR.

5 Letter Thomas Hawes (Goba) to Natal Government, 8 Aug. 1897, Min. P. SNA, 1614/1897, 1/1/252, 1/SNA; see also: Aaron Thomas Hawes Goba, Death Notice, 250/1944, Master of the Supreme Court Estates; PAR.
with exception of men’s ‘muchas,’” a loin patch hung from the waist, ordered to surrender their “clothing and skins” to be burned, and assembled—“every man woman and child”—to wash “from head to foot” in chemical solution.1

By mid-1897, colonial officials had acknowledged that they not only failed to curb the epizootic, but aroused outrage. As a consequence, they turned to less invasive strategies, namely bacteriology and germ theory, which promised a laboratory remedy. The revolutionary potential of bacteriological methods enabled medical pioneers such as Dr. Robert Koch to culture bacillus and use a microscope to expose the “enemy in unmistakable terms.”2 European imperialists hailed his breakthroughs when justifying the Scramble for Africa as an altruistic trial of science in the Dark Continent.3 This rhetoric inspired scientists in South Africa to track “the more obscure causes of disease in men and animals” at an “institute for the study of Bacteriology” in the Cape, founded in 1893 with funds from the Natal Governor. The institute’s major goal was to obtain “virus for inoculation.”4 The Natal colony deployed inoculation to control “vagrancy” and “native labourers,” with an 1894 Proclamation authorizing policemen to compel Africans looking for employment to get “vaccinated [for smallpox], or otherwise . . . submit themselves . . . for vaccination.” Non-compliance brought a heavy fine.5

In the spring of 1897 Natal authorities developed a plan to vaccinate cattle throughout the colony by using a giant syringes wholly unfamiliar to Africans. While the Principal Veterinary Surgeon spearheaded this effort, he consulted counterparts in South Africa and visiting bacteriologists such as Dr. Koch, who accepted an invitation from Cape officials to set up a laboratory in Kimberley, where he tested a “bile” vaccine made from bovine “gall, and . . . contents of the bowels.” He helped concoct this mixture, which optimally immunized cattle for three to four months, and invented a serum of blood drawn from a cow that recovered from rinderpest (called a “salted” beast).6 Bile was initially favoured as a prophylactic by the Natal Department of Agriculture, which launched the vaccination campaign with the aid of magistrates, policemen, and a handful of white settlers and missionaries certified in “Dr. Koch’s method.” The veterinary staff could not speak Zulu and

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1 Report Mag. Weenen, 3 Feb. 1894; Telegrams, 8 Feb. 1894; Min. P. CSO, vol. 1387, 1/CSO, PAR.
4 “[T]he more . . . inoculation”: Confidential Letter Cape Department of Lands, Mines and Agriculture to Natal Acting Governor, 9 Mar. 1893, CA 167/97; Letter Natal Under Secretary to Secretary Cape Prime Minister, 1 July 1897, 4460/97; Confidential Min. P. Cape CSO, 1892-1893, vol. 2570, 1/CSO; Grahamstown Bacteriological Institute, Cape Veterinarian, 1/43, 1/CVS; Cape Archives Repository (CAR), Cape Town.
relied on native affairs authorities to carry out operations in African areas.\(^1\) Border guards and pass inspectors assisted in the inoculations, along with African vaccination officers who patrolled District Surgeons' lazaretto, which sheltered smallpox patients. Most vaccinators had little medical knowledge.\(^2\)

Healthy cattle owned by colonists received the first wave of injections; then “natives who may desire to adopt this course” were proffered the syringe.\(^3\) When given the option, some Zulu-speaking homestead heads were “most anxious to inoculate,” according to one Natal official, especially when they mistakenly thought vaccination cured full-blown rinderpest.\(^4\) However, large numbers of African stock owners were either cautiously watching the results or loath to treat “clean herds,” if only because it seemed illogical to wilfully introduce illness in a healthy cow.\(^5\) Africans’ distrust of colonial intentions deepened when inoculators botched procedures, thereby elevating the already high rates of bovine morbidity and mortality.\(^6\) Notoriously unstable, bile fluid and blood serum required careful preparation; if poorly blended, they could disintegrate into a brew of rinderpest pathogens. Unwieldy syringes aggravated the problem. One inoculator dubbed them “horrible things of no earthly use,” with “three faults, first the brass needle would not penetrate the skin, the India rubber . . . bursts or is cut by the string tied round and then the bile gets behind the plunger.” Faulty instruments and lethal vaccines confirmed African beliefs that “if they inoculate their cattle, they will only die.”\(^7\) Inoculators heard more and more Africans ask: If the white man says he shields cattle from harm, why is he “bringing the disease nearer?” Some Zulu stock owners went a step further and resisted the needle. They circulated rumours of “natives rising,” effectively scaring away veterinary personnel. Not surprisingly, when

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\(^1\) “Dr. Koch’s method”: Letter Trappist Missionary to SNA, 21 Aug. 1897, Min. P. SNA, 1671/1897, 1/1/252; Min. P. SNA, 13 Aug. 1897, 1539/1897, 1/1/251; by late 1897 more “native assistants” assisted the vaccination process: Min. P. SNA, 26 Dec. 1897, 2914/1897, 1/1/269; 1/SNA, PAR.

\(^2\) There were perhaps two dozen experienced bovine inoculators. Border guards: Letter G. Daniel, 13 Aug. 1897 to SNA, Min. P. SNA, 1541/1897, 1/1/251; Letter A. Ball to SNA, 31 Aug. 1897, Min. P. SNA, 1810/1897, 1/1/254; vaccination officers doubling as lazaretto guards: Min. P. Mag. Weenen, 16 Sept. 1897, 3/2/2, 1/WEN; one of the thirteen government veterinarians or their assistants usually certified rinderpest inoculators; their operations: Min. P. SNA 12 Oct. 1897, 2206/1897, 1/1/258; 1/SNA, PAR. The lazaretto derived its name from Lazarus, the pauper with boils who reached salvation in Abraham’s bosom: S. Lock, et al. eds. *The Oxford Illustrated Companion to Medicine*, (Oxford: Oxford University Press, 2001), 471.

\(^3\) European-owned cattle vaccinated first and “natives who . . . course”: Min. P. SNA, 16 Aug. 1897, 1784/1897, 1/1/253; Min. P. SNA, 5 Aug. 1897, 1483/1897, 1/1/250; vaccines were monopolized by white farmers: Min. P. SNA 16 Dec. 1897, 2933/1897, 1/1/267; some white farmers believed that African cattle required inoculation: Min. P. SNA, 19 Nov. 1897, 2645/1897, 1/1/266; 1/SNA, PAR.

\(^4\) The Africans who requested inoculation during bile and blood vaccine phases were in the minority; “most . . . inoculate”: Min. P. SNA 30 Aug. 1897, 1766/1897, 1/1/253; also: Min. P. SNA, 5 Aug. 1897, 1487/1897, 1/1/250; support for vaccinating African cattle came from settlers seeking work as paid inoculators: Letter G. Francis (“natives are now clamouring”), 14 Aug. 1897, Min. P. SNA, 1550/1897, 1/1/251; Africans believing the bile method cured rinderpest: Min. P. Mag. Weenen, 21 Aug. 1897, Min. P. SNA, 1645/1897, 1/1/252; 1/SNA, PAR.

\(^5\) African distrust of prophylactic injection: Letter Rinderpest Commissioner, Umlazi, to SNA, 9 Sept. 1897, Min. P. SNA, 9 Sept. 1897, 1967/1897, 1/1/255; African ambivalence toward inoculation and vaccination results: Min. P. SNA 16 Aug. 1897, 1725/1897, 1/1/253; Min. P. SNA, 4 Sept. 1897, 1893/1897, 1/1/254; 1/SNA, PAR.

\(^6\) High rates of bovine morbidity and mortality among vaccinated African cattle: Min. P. SNA, 14 Aug. 1897, 1582/1897, 1/1/251; Diary of Supervisor Native Locations and Rinderpest Inoculator, Umgeni, Min. P. SNA, 2 Nov. 1897, 2236/1897, 1/1/258; white farmers lost far fewer inoculated cattle; colonists “experimenting among the kafir herds”: Report of Inoculator Ixopo, 7 Dec. 1897, Min. P. SNA, 2837/1897, 1/1/268; Letter M. Stewart to SNA, 26 Aug. 1897, Min. P. SNA, 1747/1897, 1/1/253; 1/SNA, PAR.

\(^7\) “[H]orrible . . . . plunger”: Letter Brother Nivard to USNA, 4 Sept. 1897, Min. P. SNA, 8 Sept. 1897, 1900/1897, 1/1/254; flawed syringes jeopardized inoculation: Min. P. SNA 25 Aug. 1897, 1906/1897, 1/1/255; Letter Rinderpest Commissioner Royston to SNA, 28 Aug. 1897, Min. P. SNA, 1761/1897; “if . . . die”: Report Inoculator Umlazi, 17 Nov. 1897; Min. P. SNA, 2547/1897, 1/1/264; 1/SNA, PAR.
smallpox re-emerged in late 1897 and District Surgeons bungled “native [human] vaccinations,” African children were kept from the ominously familiar inoculator.\(^1\)

These varied responses reveal how Africans brought “their own epistemologies of causation and cure” as well as a degree of openness to encounters with European biomedicine. Their receptivity to colonial remedy, however, plummeted when the syringe conveyed contagions. Some Africans scorned veterinarians by calling vaccinator’s instruments the embodiments of “witchcraft,” \(\text{umthakathi}\).\(^2\) When bile extraction required the dissection of a rinderpest-infected cow, African suspicion could multiply; post-mortem procedures exposed massive internal deformities. Accusations of witchcraft could be validated by the existence of mutilation. Other confirmations of \(\text{umthakathi}\) probably occurred when Africans saw a pass official perform \(\text{ukugcaba}\), lancing the cow skin, in this case near the jugular vein. Other synonymous phrases for \(\text{ukugcaba}\) were “to inject vaccine” and “to deliver abuse.”\(^3\) Months earlier, this same official might have harangued onlookers to move into a disinfecting room, where after eyeing the “Perfect Purifier,” one government observer commented, they exhibited “their first fear of . . . ‘Umtagati [sic].’”\(^4\)

Zulu folklore told of intimates of \(\text{umthakathi}\), the dwarf-like \(\text{imikhovu}\), appearing around “the outbreak of rinderpest,” seizing travelers, and sometimes slicing their skin.\(^5\)

Unease about bovine vaccination resonated in the Zulu language. The common verb to “inoculate, vaccinate, inject,” \(\text{ukujova}\), likely entered speech at the time of rinderpest, when a sinister term, \(\text{ujovela}\), had currency. In Reverend Colenso’s classic \(\text{Zulu-English Dictionary}\)—completed in 1861, re-published in 1884 and then updated in 1905—\(\text{ujovela}\) merits an entry but, significantly, \(\text{(uku)jova}\) does not yet appear. Even more telling, \(\text{jovela}\) is defined as a range of toxins, often conjured by an \(\text{umthakathi}\), which convey a sexually transmitted disease. This malady, like rinderpest and AIDS, visibly wastes its victims. \(\text{Jovela}\) afflicts “an adulterer by his having intercourse with another man’s wife, after the husband, suspecting her infidelity, has taken \(\text{umsizi}\) [medicinal powder linked to \(\text{iZembe}\)] and lain with her. The woman in this case will not be diseased, but yet is supposed to communicate disease to her paramour, who grows weak in his limbs, falls away in his flesh, and dies.”\(^7\) The


\(\text{2 Vaccination instruments as } \text{umthakathi} \text{: Report of Inoculator Ndwedwe, 12 Feb. 1898 (14 Feb. 1898), Min. P. SNA, 12 Oct. 1897, 2236/1897, 1/1/258, 1/SNA, PAR.}


\(\text{4 Letter Superintendent Border Guard, District 34, Umtwavuma Drift, 20 July 1897, Min. P. SNA 8 July 1897, SNA 1233/1897, 1/1/249, 1/SNA, PAR.}

\(\text{5 Testimony of Mkando, 13 Aug. 1902, in James Stuart Archive, 3 (1982), 170; Testimony of Mageza, 21 Feb. 1909, } \text{ibid.}, 2 (1979), 78. In the 1850s, supernatural dwarfs supposedly appeared during cattle lungsickness and smallpox outbreaks in the Zulu kingdom: Testimony of Mthayankomo, 10 Jan. 1922, } \text{ibid.}, 4 (1986), 107-109.}


\(\text{7 Rev. J. W. Colenso, Zulu-English Dictionary (Pietermaritzburg: P. Davis & Sons, 1884), 230, 519, 659; } \text{ibid} \text{ (Pietermaritzburg: Munro Bros., 1905), 243. See also relevant evidence: Testimony of Mkando, 17 Aug. 1902, in} \)
compiler of another comprehensive *Zulu-English Dictionary* (1905), missionary-ethnographer A.T. Bryant, noted the “recent” origins of *ukujo*. The next term listed, *ujovela*, is followed by one synonym, *i-Zembe.*

**“People Have Lost Respect for the Taboos”**

Today, Pentecostal movements in KwaZulu-Natal pulse with calls to build a moral bulwark against deadly sexual pollution. In late August 2001, for example, an African minister of a revivalist church near Pietermaritzburg opened her sermon with an admonition. She advised worshippers, particularly mothers and daughters, that true healing and life-giving power sprung from penitence, *ukuza*, which kept “death [from] stalking everyone.” After denouncing the sins of fornication, she laid out a path of proper conduct, *ukuwayezayo umnthetho*, and cleansing, *ukuHLanza*; unmarried congregants were told to be abstinent; husbands and wives were implored to be faithful and go forth and multiply. She also broached the matter of “immoral” interference with fertility, reflecting broader African apprehensions about birth control.\(^3\) The geographer Mark Hunter is exploring this discourse in KwaZulu-Natal, charting the popular hostility toward condoms and, strikingly in light of rinderpest inoculation, “men’s attempts to prevent women from jova-ing,” i.e., to inject the contraceptive Depo Provera.\(^3\)

The preacher then turned to the subject of mortality. She spoke of a sorrowful trinity made up of women, children and bereavement, proclaiming, “women and children mourn, while men carry on”; she also cautioned against giving in to “mourning fatigue” (*sakhathala ukuza*).\(^4\) In her pioneering investigation of Africans “living and dying with AIDS,” the sociologist Tessa Marcus examined similar sentiments in KwaZulu-Natal, which revealed the exacting toll of bereavement on families. Widows were required to wear black clothes in the heat and enter virtual seclusion for months at a time, Marcus reported; during this solemn period children were also commanded “not to make any noise” or “go out with their friends.” By contrast, older men were largely relieved of these everyday avoidance prohibitions. A widower within months of his wife dying of AIDS, for example, could be presented with “someone else,” a partner secured by women in his own family. The new companion understood that she was to restore his domestic equilibrium by affirming his masculine prerogatives in the public and private spheres.\(^5\)
Elderly informants in the Midlands-Pietermaritzburg region and Thukela valley told me that more rigid bereavement obligation could kindle generational discord. Some youths vented their impatience with ukuzila, raising anxieties among their guardians that rituals of remembrance were not respected. Moreover, relationships between parents and children could become frayed during funerals. One adolescent informant recalled that during a 2002 night vigil for a peer (and victim of AIDS) in Umlazi south of Durban, the deceased’s friends arrived in scanty dress. They left just before morning with boyfriends to attend a nearby “after tears” bash, where they “carried on,” contravening the solemn mood of ukuzila. The informant was confronted a day later by her aunt, who felt the loud revelers “insulted the family . . . and had no discipline.” Between 2002 and 2003, the older fathers I interviewed invariably saw “after tears” parties as a sign of joblessness. They pointed to idle young people who spend the little cash they have on sebenza, partying, and monetary gifts for lovers. Such pursuits not only breach ukuzila; they drain scarce family resources that fund burials. In this sense youths were faulted for bringing shame and misfortune precisely because they ignored customary discipline, inkuliso.

In a study of how several male generations envisage inkuliso and AIDS, the historian Mxolisi Mchunu explains what could happen to a young Zulu man who did not “behave [with respect] . . . amongst other people, amongst his peers (Ontanga), and amongst elderly people.” Disappointed guardians could berate the transgressor as “a growth or tumour” who emerged from his mother’s womb. Those who breach inkuliso by engaging in premarital intercourse could incur harsher censure. A father who lost his son to AIDS in rural KwaShange (Midlands-Pietermaritzburg region) told Mchunu that the deceased was heedless of ancestral teachings and “sexually irresponsible.” Mchunu observed that other parents “who know about AIDS are not sympathetic towards the dying child.” If the stricken person was a young man, they denounced his lovers: “‘We warned you not to behave anyhow with girls but you wouldn’t listen—look, you are causing us problems now—we have to look after you like a baby, and where are your girlfriends now (they have run away).’” This rebuke articulates a “belief of older Zulu informants that HIV/AIDS is only killing the African younger generation, and not older people or white people, because these young people have lost respect for the taboos associated with the correct behaviour regarding sexual matters.”

A Zulu-speaking widow in Pietermaritzburg told me that “promiscuity and ukufa” are rife because “no one marries anymore.” In her opinion, if a couple could afford to formalize its relationship, fidelity would be more important. The pandemic, however, places this

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possibility out of reach. “With so many people passing,” she lamented, “we now worry that we will become [even] poorer,” which will “make marriage even less likely.” When asked whether she thought family life might disintegrate, she replied: “I don’t know, truly. We are made quiet by this ‘annihilation.’” KwaShange residents interviewed by Mxolisi Mchunu elaborated on their dread of ububane, meaning to “suffer annihilation.” One informant relayed that older “people dying in the rural area are said to die from other causes, like heart attacks, cancer and the like.” Yet mortality among young people is attributed to “taboo breaking and the curse of death via HIV/AIDS.”

A Zulu-speaking grandfather in Makhabeleni (Thukela valley) echoed these views and suggested another dimension to ububane. “Death was always the result of odd misfortune,” he explained in an interview with me, “or when ‘ripeness’ [advanced age] . . . called elders home” to “a good death,” ukugoduka. Now, he asked rhetorically, “Why had death become a matter of ‘extinction?’” He answered by recounting memories of radio programmes in the late 1990s that chronicled a sordid confessor (umvumi onamanyala), a white doctor who planned to release poison on black people (ukudlisa abantu noma ukubulala ngobuthi). Older men in the grandfather’s district considered this “doctor of death” (referring to Wouter Basson, head of apartheid biological warfare projects) to be the mastermind of AIDS. The rural grandfather dismissed “this kind of gossip,” but his neighbors found it jarringly odd that the pandemic emerged after democracy only to strike “abantu, the (black) people, moving freely for the first time,” while “whites (abelungu) . . . were untouched.” A parallel sentiment reverberated in KwaShange. In a haunting dream recollected for Mxolisi Mchunu, a young male informant described “giant glittering black and white snakes and a horse with an upper body of a white person.” “The community understanding of his vision,” Mchunu writes, “is that the snakes are his brother, who died of AIDS and his mother who died more or less at the same time (of unknown causes), who had come back in anger at his having not been there while they were sick.” But “to see a white person is indicative of misfortune.”

Conclusions

Mchunu’s path-breaking inquiry into Zulu perceptions of discipline, sex, and mortality suggests that historians could usefully compare rinderpest-era expressions of shame and blame to the stigmas of AIDS, thereby gaining insight into the “unspeakable” dynamics of the current pandemic. Yet caution should also be exercised, if only because from at least the late nineteenth century to the present, fatal outbreaks necessitating Western intervention did not engender uniform hostility from Africans. While many saw white treatment as a forerunner of malevolence, others welcomed modern medical care, which sometimes integrated elements of traditional healing and scientific principle.

5 For example, in the late 1930s Zulu medical aid Edward Jali (who later joined public health pioneers Drs. Sidney and Emily Kark) recommended preventive care in rural Natal reserves racked by typhoid and tuberculosis: L. Vis, “‘We Sow the Seed’: Perspectives of Health Educators at the Institute of Family and Community Health in Durban in the 1940s and 1950s,” (MMSC thesis, University of KwaZulu-Natal Medical School, 2005), 110. Jali’s explanations of disease causality, couched in the language of Kochian bacteriology
Finally in the quest to expand existing knowledge of the continuities between rinderpest and AIDS, for example, one could look no further than today’s headlines about Western-sponsored health campaigns. Elsewhere in the Sub-Saharan region, like Nigeria and Burkina Faso, where Islam threads moral, political, and spiritual life, the World Health Organization effort to eradicate polio has met resistance. This immunization plan is seen as a conduit for Western evildoers to inject AIDS, not a polio vaccine, into Africans.¹

and Zulu cosmology, were summarized in a letter to James McCord, the doctor who cataloged the human costs of rinderpest. Jali’s Zulu origins and association with Dr. McCord: Form of Application, South African Native College, 22 Jan. 1924, Jali Student File, Registrar’s Office, Fort Hare University, Eastern Cape. I thank Prof. Robert Edgar for this reference.

The Search for Healing: 
the AIDS Epidemic in Gwembe Valley

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How people respond to their own and others’ illnesses due to AIDS depends in part at least on timing: timing with reference to occurrence within the time span that AIDS related illnesses have been known and to other occurrences within the same support group, and a personal history of being ill or providing support to others. Responses also reflect national and family resources and the resources and social status of an individual patient. In Zambia, cabinet ministers are flown to South Africa for treatment at government expense even when death is imminent while most citizens have no access to ARVs and government health centres lack other medications. This paper uses data from the Gwembe Tonga longitudinal study to examine how the search for healing and the ability to mobilise support systems have varied over a twenty year period as Gwembe Tonga first became aware of the threat caused by the spread of HIV and then tried to deal with it. Their responses built on a recognition of increased morbidity and mortality among kin and neighbours, information campaigns about the nature of HIV, an increasing ability to diagnose symptoms as indicative of AIDS, and continuing reappraisals of both western explanations (biomedical and religious) of how HIV is transmitted and the efficacy of western and traditional medicine to treat and cure. But how people have responded has also reflected perceived obligations to support kin and the variability over time of familial and national resources, for these limit what can be done whatever one thinks should be done in a search for a cure or the sustaining of those who are ill.

Material for this paper derive from a long-term study of Gwembe Valley initiated in 1956 by myself and Thayer Scudder. Information on the study are to be found in Thayer Scudder and Elizabeth Colson, “Long-term Research in Gwembe Valley”, in George Foster et al., eds, Long-term Field Research in Social Anthropology (New York, Academic Press, 1979), 227-254; “Long-term Research in Gwembe Valley, Zambia”, in Robert V. Kemper and Anya Royce, eds, Chronicling Cultures: Long-term Field Research in Anthropology (Walnut Creek, Altamira Press, 2002), 197-238; Lisa Cliggett, “Multigenerations and Multidisciplines: Inheriting Fifty Years of Gwembe Research”, in Kemper and Royce, eds, Chronicling Culture, 239-51. Initially field work was supported by the Rhodes-Livingstone Institute (later the Institute for African Studies and now the Institute for Economic and Social Research in the University of Zambia), and thereafter by various agencies including the Social Science Research Council, the National Science Foundation, and for Scudder, the John Guggenheim Foundation. Over the almost fifty years of the study we have been indebted to many people both in Zambia and elsewhere, and especially to village research assistants and the people of Miyaka, Mpwe, Chezia, and Siameja neighbourhoods in what are now Siavonga, Chipempe, and Sinazongwe Districts. Dr Thea Savory has been most helpful in alerting me to recent developments in the ARV programmes and responses to these. Lastly, Iam indebted to Thayer Scudder, Lisa Cliggett, and Brendan Carmody for comments on an earlier draft, and to the members of the Berlin seminar on “AIDS and the Moral Order in Africa”, most especially Christine Obbo and Ute Luig, for their comments on the draft presented at the conference on 3-6 March 2005.
The context

Much that is said here will resonate with what has happened and is happening elsewhere in Africa, but I am dealing with the impact of AIDS at a particular place and time: the Gwembe Valley of Zambia’s Southern Province1 in the decades after 1980. For data, I draw upon the Gwembe Long-Term Study of Social Change initiated in 1956 long before AIDS was known. My last visit to the Valley was in 2006.

In the slightly over twenty years since the mid-1980s, when Zambians, including the people of Gwembe Valley, first became aware of the existence of a new threat to their existence identified under the rubric AIDS, they have gone through a series of responses, including denial – denial that AIDS existed in their country, and then, denial that it could be involved in one’s own illness or the illness of one’s kin. Denial in itself was a sign that they refused to give up hope of a cure, and this justified the continued search for a cure. As long as it was possible to cling to denial, any illness due to HIV/AIDS was likely to be assimilated to previously known illnesses. Indeed, many were previously known illnesses taking advantage of impaired immune systems. So long as illnesses were not identified as AIDS related illnesses, they raised no particular new moral issues, even though illness episodes were recognised as costly in that they involved medical fees and the loss of wages or other forms of productivity by patients and caretakers. This was nothing new. Illness was a fact that had to be faced like other difficulties that required decisions about what people could do under given circumstances. Very often this meant a balancing of various obligations, not all of which could be met at the same time.

From the beginning, people’s responses to AIDS were affected by the fact that it was but one of many difficulties with which they had to contend in the last decades of the 20th century and the early years of the 21st. The epidemic emerged when Zambia was already in trouble, due first to the decline of the national economy dependent on copper exports when copper prices fell on world markets in 1973 while prices of imports rose rapidly, and then beginning in the 1980s to structural adjustment programmes urged upon a now indebted country by the World Bank and the International Monetary Fund. The public health system was one victim of the economic decline. Retrenchment here coincided with emergent drug resistance of various diseases, including malaria. Climatic change also became apparent with more frequent drought years beginning in the early 1980s: this meant more years when survival depended on access to imported food and people still went hungry.

Moral dilemmas

My understanding of how Gwembe Tonga have responded to the epidemic, as to other difficulties, is influenced by what I have learned over fifty years of their premises about the human condition. First, they stress the importance of personal autonomy. They do not like to be told what to do. People should make their own decisions. But in doing so they should take into account what can be summed up as a moral order. This means that they expect to give consideration to how their obligations to others restrict their freedom of action. In practice, this usually means obligations to kin. But the ramifications of kinship mean that everyone is faced with many competing claims. One of the arts of Gwembe life involves creating claims on others that they can be shamed into acknowledging while at the same time avoiding claims upon oneself.

Life had always been difficult in the Valley whose people were accustomed to drought years and food shortages as well as the epidemics characteristic of the first half of the 20th

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1 Gwembe Valley is the local term for the Middle Zambezi Valley, the river formerly providing the boundary between what are now Zambia and Zimbabwe. Much of the valley floor is now occupied by Kariba Lake formed when the Zambezi River was dammed at Kariba Gorge in 1958.
century. Certainly, food shortages and epidemics can create moral dilemmas, but on the whole Gwembe people, are realistic pragmatists who try to meet obligations when they can but know that on occasion they will fail and then must live with the knowledge of failure. Village memories include much that is grim. Most families have secrets that should not be mentioned, for village society depends upon a willingness to recognise that even if people behave badly on occasion, they remain members of the local community. In hunger years, people may be forced to triage and decide who should be fed and who go hungry. In the 1940s, while working on the nearby Plateau, I met women who had been sold as children by their Gwembe kin for the grain that fed their elders. Even in the 1980s and 1990s people whispered of elderly men and women, or someone badly disabled, left to starve during bad hunger years and of people who survived through theft of the scanty food resources of kin and neighbours. People thought this shameful, but understandable.

Decisions about whom and when to help were based on premises other than the western one that life must be preserved at all costs. People would probably agree that one is obligated to assist kin who are ill and to participate in mourning both kin and neighbours. The obligation to contribute funds to pay for a cure is recognised, though not always met, if cure seems probable. On the other hand, it is difficult to refuse help when you see no hope, for that means you open yourself to a charge of witchcraft since only a witch could speak this confidently. The obligation to feed and care for the ill continues to exist even though the case is hopeless, but people must still decide whom to help and how much to give. They have rarely had the luxury of being able to afford infinite compassion. The sense of obligation is tempered both by the nearness of ties of kinship and by an appreciation of help received in the past or expected in the future. Even though many are now Christians aware of the teaching of their churches on the sacredness of all human life, this does not relieve them of the need to allocate scarce resources among the many with claims.

In the past, people made decisions about who should live. Children born with obvious disabilities, along with those regarded as anomalies, were either killed at birth or allowed to die, and I have known elderly Gwembe Tonga deplore the use of drastic measures to keep premature babies alive. Better, they said for the weakling to die and the parents try again to produce viable children. People might also leave the very ill untreated on the premise that death was inevitable, and those who were very ill might decide to hasten death by refusing food and water and have their decision respected. Against this was the fear that those who died neglected by their kin would become *ibandwa*, vengeful spirits of those dying aggrieved at bad treatment or failure to provide proper mourning who return to punish descendants or lineage members for neglect.

Only matrilineal kin, however, had an obligation to care for the ill and dying until health centres and hospitals were established: even then kin were expected to accompany and nurse those admitted. It was generally agreed that only lineage kin, or perhaps a man’s children, would nurse someone no longer able to take care of bodily functions, though sometimes wives cared for incontinent husbands. People did care for ill and dying kin, for various reasons: empathy, fear of how spirits would reciprocate after death, or a thought to reputation since while their neighbours might not hold to account, they judge them. Support for those ill and in need, therefore, was and is based on complex considerations, that give rise

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to many possibilities for anxiety, discontent, and a sense of exploitation on the part of both those who give and those who receive.

When one can not adequately fulfill obligations either to the living or the dead, it is appropriate to make a gesture indicating a desire to do one’s duty. Debtors acknowledge their debts even if they do not pay them, just as people may provide only a token acknowledgment of their obligations to the spirits of the dead when they can do no more. In a hunger year, when there is no grain for brewing when a divination finds that a spirit is demanding beer, the solution is to offer using water in which a few grains have been put to soak, informing the spirit that beer will be offered when it is possible to brew. Or someone living in an urban area, where it is held offerings cannot be made, pours water beside a tree at the edge of town, while assuring the spirit that beer will be provided on return to the village. So also with the ill, care may be minimal, a token of what one might do in other circumstances.

For most Gwembe people, life involves frequent compromises, between the ought and the possible. Responses to the AIDS epidemic involve such compromises. The help people give varies from case to case reflecting knowledge of HIV/AIDS, appraisal of resources available for underwriting treatment or to cushion a patient who is ill and dying, an evaluation of the likely outcome of treatment, fear of becoming infected, fear of being stigmatised by the community if the illness is identified as AIDS, and fear of future vengeance if a spirit departs life angered by neglect. With the massive flocking to churches in the 1990s, the teaching especially of charismatic churches that HIV/AIDS is God’s punishment for sin or due to Satan, also affects how people view those ill with AIDS and their right to support.

For a decade or more after AIDS was first known, many considerations discouraged people from being willing to label an illness, whether their own or that of a kinsperson, as AIDS related. Whatever else they knew about HIV/AIDS in those first years, people heard early on that a diagnosis of AIDS was tantamount to a death sentence. In Zambia, in fact, death usually occurred within about two years after the first appearance of full-blown AIDS. People were also told that HIV/AIDS was spread through sexual intercourse, assumed to be illicit, with the implication that the one afflicted was responsible for the illness and the problems this caused others. When the ill denied that they had AIDS, they denied both that responsibility and their own imminent death. Refusing the label and looking to other diagnoses with a better outcome justified requests for help and the use of family resources for a member seen as temporarily in need of support.

By the end of the 20th century, denial began to break down in the face of the massive epidemic and the diagnostic skills acquired through watching what happened to kin and other associates. People began to live with the knowledge that they could do nothing to bring about a cure. Then, in the early 21st century, the arrival of ARV therapy confronted those who knew of it with new dilemmas, for the cost was prohibitive for all save the rich or the powerful. The remainder of this article looks at these developments more carefully within the time frame through which the epidemic has been known.

The onset

On returning to Zambia in 1982, I was puzzled at the number of men, known to me as boys in the 1940s when I worked on the Plateau, who had died since my last visit to Zambia in 1978. Usually, it was said, from pneumonia. The late 1970s and early 1980s were hard times for Zambia, but that hardly accounted for the death of so many men in their forties or early fifties, a time of life when few deaths were expected. Neither I nor probably anyone else in Zambia in 1982 knew anything about AIDS: it was only late in 1982 that I read reports in American newspapers and journals of unusual physical symptoms and an unusual number of deaths in

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among younger men in the United States. Shortly thereafter, the term AIDS was invented to designate the phenomenon, but biomedicine was still uncertain about how it had originated, how it spread, and who might be at risk. The HIV retrovirus was not identified until the following year.\(^1\) Since the reports cited a form of pneumonia as one of the AIDS associated illnesses, I then wondered if here lay an explanation for what had seemed to me to be an abnormal number of deaths among Tonga-speaking men I had known as youngsters and perhaps also for more frequent references to cases of tuberculosis 1982 when tuberculosis had seemed largely under control by 1972.

I now suspect that by 1982 many in Southern Province harboured HIV and that those deaths in the late 1970s or early 1980s represented the beginning of mortality due to HIV/AIDS and also signalled increasing morbidity as various diseases attacked already compromised immune systems. The timing is not unlikely. Lwanda, extrapolating from later rates, believes that HIV reached Malawi about 1977 and was implicated in the observed increase in unexplained deaths of urban youths in the early 1980s although the first hospital diagnoses in Malawi came in 1985.\(^2\) But in 1982, neither on the Plateau nor in Gwembe Valley, did people suggest that they thought themselves confronted with something new. This was very unlike their response to the influenza epidemic of 1972 when they mobilised as communities to drive out the illness. Nobody dwelt on symptoms later regarded as indicative of AIDS, such as swollen legs, emaciation, and diarrhoeas. Emaciation and diarrhoeas were present, but emaciation was associated with a shortage of food due to poor harvests, low wages, or unemployment, and diarrhoeas with dysenteries long common to the region, just as pneumonia had long been present. These were old problems. They were known to respond to treatment, and were dealt with either by old African remedies or by a resort to biomedical treatment at hospitals and rural health centres even though the decline in the Zambian economy was already beginning to affect the quality of care and availability of medicine at the centres. If people were perturbed by a larger number of deaths or a greater number of illnesses, they did not say so. Therefore, in Gwembe Valley, as in the West, the first impact of HIV/AIDS went largely unnoticed at the conscious level, though it may have heightened the general unease of the early 1980s and helped to trigger the spate of witchcraft accusations and summoning of witchfinders\(^3\) that occurred throughout Southern Province in 1981 and 1982 as neighbourhood after neighbourhood tried to identify and nullify the witches who caused illness and death.\(^4\) It is more likely that people were responding to the general economic and political malaise that affected Zambia, including Southern Province, from the mid 1970s, made the more bitter because it followed on the economic buoyancy and ebullient expectations of a better life associated with the coming of independence in 1964. In 1982 people seemed more deeply depressed about their circumstances than they had been even after their forced resettlement when Kariba Hydroelectric Dam on the Zambezi River flooded much of their former territory in 1958. They were bitter that their hopes were being frustrated. They talked of the scarcity of jobs and commodities, the decline in government services, and the bleakness of the foreseeable future. It was to these that Scudder attributed “the community unravelling” he perceived at that time.\(^5\) The early 1980s was also a time of drought, which meant hunger and dependence on imported grain. The AIDS epidemic was too insidious to

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\(^1\) *Ibid.*, xi.


\(^3\) A witchfinder is a diviner who specializes in the diagnosis of witchcraft and the identification of witches.


compete with all the rest that frustrated hope and raised anxiety to be a major cause of concern.

**The Growth of Knowledge**

In the twenty years following 1982, the people of Gwembe Valley, like their contemporaries elsewhere in the world, went through various phases of denial and acceptance, as knowledge of HIV, its transmission, and effects upon the human body became available and spread. As Schoepf\(^1\) noted, most countries in Africa went through a stage of denial early in their experience of the epidemic. The warnings that began to circulate in the late 1980s, largely stemming from the United States and Europe, gave people little information on how to act, due to the early uncertainty among biomedical workers as to whether they were dealing with one or a number of diseases, what the modes of transmission might be, and the prognosis. Schoepf also points out that the lengthy incubation period between infection and first physical symptoms encouraged uncertainty and made it difficult for people to accept that someone who looked healthy already carried a fatal infection that could be transmitted to others and would end in death within a few years.

Zambians may have been inclined to give more credence to the epidemic when President Kenneth Kaunda spoke on Radio Lusaka late in 1988 to announce the death of his son from AIDS and warn of the need to take precautions against infection. Most Gwembe people still thought that even if the threat was real it was unlikely to affect them: AIDS was something that happened in other countries.

In 1987 I recorded the first known deaths from AIDS in our longitudinal sample population, which includes all resident in four Gwembe villages in 1956-57 and subsequent census years, whether they remained resident or moved elsewhere, and their descendants.\(^2\) These first deaths were of two men in their early thirties who had gone to secondary school and then worked in Lusaka where they were treated and diagnosed at the University Teaching Hospital. I learned of the diagnoses from friends who saw the hospital records. At that time, Zambians still had access to free medical care, and for many, especially in urban areas, the first choice of treatment was biomedicine, dispensed at government hospitals or health centres, even though they might also use home remedies, visit an African practitioner, and consult diviners to discover the underlying cause of the illness in witchcraft, the anger of the spirits of the dead over neglect, or spirit possession.

In the village from which the men came, no one openly associated their deaths with AIDS even though by 1987 people had begun to talk of illnesses and deaths, especially among young educated town-based elite, from what some called “slim disease” although AIDS had already entered the national vocabulary. In Gwembe villages, the mode of transmission was beginning to be known. Some at least knew that there was no known cure for the condition even if particular manifestations might be temporarily overcome. They found it difficult to accept that transmission was through sexual intercourse. For one thing, they had long been familiar with sexually transmitted diseases introduced through labour migration, and knew these could be cured with antibiotics. There was also the fact that some remained healthy who were known to have had numerous sexual partners.

By 1990, 99% of the women interviewed for the Zambian Demographic and Health Study reported that they had heard of HIV/AIDS, and 90% knew that AIDS was transmitted through sexual intercourse. This was true of both rural and urban women, and did not differ

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by province. Fewer women knew that AIDS could be transmitted through shared needles or razor blades or blood transfusions, or that it could be transmitted from mother to child.  

Gwembe women can be assumed to have been as well informed as those interviewed for the Study, for they attended health centres and the majority of them had experienced town life either as residents or as visitors to kin or in search of medical treatment or for education. Some were traders who sold rural produce on urban markets. By the 1990s, one could think of Zambia as essentially forming a single disease and knowledge pool.

By 1992, the effect of AIDS on the longitudinal sample was evident in reports of illnesses and deaths. But whatever people admitted to knowing, by then HIV/AIDS was a stigmatised condition. This meant that whatever knowledge people displayed with respect to HIV/AIDS in the abstract, they were not prepared to admit that they themselves or any of their kin might have AIDS, nor did they speak of fellow villagers or other close associates as ill from AIDS. At most people were willing to say “he has swollen legs (or is very thin)”, or “some might say it looks like AIDS”. By 1996, people admitted that fellow villagers as well as those in other villages were ill or had died from AIDS, but they gave other diagnoses when kin showed the same symptoms. Only in 1998, did I hear men and women attribute AIDS to kin, and then it was usually only if they were living in different homesteads.

Those affected and their supporting kin clung to other diagnoses. Recognising symptoms associated with tuberculosis, malaria, or dysentery, or some other condition long familiar to them, they identified each manifestation as a specific disease, as indeed it was, treatable by biomedicine, for antibiotics had brought cures for tuberculosis, dysentery, and pneumonias. When this failed them, it was common to claim that biomedicine was mistaken about the condition and lacked knowledge of how to treat it. What biomedicine called AIDS, many said, was an illness previously known to Tonga-speakers as kahungo or chihungo, acquired through contact with a woman who had not been purified after miscarriage or stillbirth, and its treatment was known to some practitioners of African medicine. In a search for better biomedical treatment people might move from rural health centres with their limited resources to nearby hospitals or to the University Teaching Hospital in Lusaka or consult some of the private clinics beginning to appear in larger urban centres where biomedical treatment could be obtained by those with enough money. They also moved around the countryside in search of an African practitioner who had effective medicine for the condition, sometimes on the advice of workers at the Health Centre who told them this was a matter for African rather than European medicine. Treatment by an African practitioner might cost them substantially more than the fees paid to health centres and government hospitals, but so long as they had funds and some confidence in the treatment they were prepared to pay. Some used every resource available, using biomedicine to treat the specific manifestation and African medicine to rid themselves of the disease itself. In the early 1990s, questions about people in the village censuses frequently brought the answer that they were staying elsewhere in Gwembe Valley or on the Plateau being treated by an African practitioner though the nature of the illness was left vague.

In appraising early reactions, it is important to remember that many of the first Gwembe AIDS patients known to me were members of the educated elite who were likely to look to biomedicine for cure. Unlike those maturing in the early 21st century, they had grown up in a Zambia where immunisation of children, beginning in the 1960s, controlled many childhood diseases, malaria had been practically eliminated in the 1960s and early 1970s through the use of DDT, antibiotics rapidly cured many previously intractable ailments including tuberculosis, even leprosy was being successfully treated, mortality rates had fallen

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2 H. Mogensen, *Aids is a Kind of Kahungo that Kills* (Oslo, Copenhagen, Stockholm and Boston, Scandinavian Universities Press, 1995).
drastically, and life expectancy was steadily rising. By the mid 1980s, however, the antibiotics and anti-malarial drugs which had given biomedicine its high status in the 1960s and 1970s were less effective as drug-resistant strains began to appear. Then when biomedicine could diagnose AIDS as implicated in an illness and provide information on one’s HIV status, but had no cure, people preferred to trust in African resources, which they knew had provided effective treatment for some conditions in the past. The diagnosis and prognosis provided by biomedicine which gave no hope of cure, were repudiated, and they sought support elsewhere, among practitioners of African medicine including those who claimed to heal through the use of new forms of spirit possession.\(^1\) It was only in 1996 and later that I heard people, whose children had already died after a search for treatment, comment that a practitioner of African medicine who said he or she had a cure was lying and only wanted your money. They might still clutch at hope by claiming that an illness involved witchcraft and a cure was possible if the witch could be identified and forced to counteract his attack. At this stage, it was common to hear people say that if witchcraft were involved, then it could not be AIDS, whereas if AIDS was involved it could not be witchcraft. In 1996, most funerals still involved a consultation with a diviner as to the cause of death, and now for the first time I heard divinations announced attributing the death to AIDS rather than to witchcraft or the ancestors. Mothers especially might refuse to accept the divination and continue to insist that it was witchcraft.

As AIDS became more common, frustrated anxieties had become manifest in frequent resort to witchfinders throughout the 1990s. The young, especially those in rural areas, believed that they were being exploited by senior kin who worked them hard without sufficient reward and were intent on enriching themselves through medicines that drained the life force of others. They retaliated by calling in a witchfinder to detect and destroy the charms of an individual suspect or cleanse an entire village or neighbourhood of its witches. Such treatment too came at a cost, usually of four cattle or their equivalent for each witch identified and cleansed, but hope justified it.\(^2\)

When witchfinding had been tried, and people continued to fall ill and die, other possibilities also began to be canvassed. At the end of the 1990s, people began to speculate that HIV/AIDS was a punishment for their neglect of old rituals and taboos which had kept them in harmony with the spirits of the dead and the spirits associated with the land and that it might be wise to reinstitute them. Meantime, in Gwembe Valley, as elsewhere in Zambia, beginning in the 1980s but escalating in the late 1990s, there was extensive experimentation with newly arrived charismatic churches, especially those associated with the Faith Gospel movement or Universal Church stemming from the United States. While these may preach that AIDS is punishment for sinful sexual activity, or something sent by Satan, they also preach that a strong enough belief in Jesus, frequently assessed by a willingness to contribute to the finances of the church can heal any illness as well bring prosperity in this world. Some of them claim to heal through the laying on of hands.\(^3\) In a search for healing, people move from church to church much as they have tried to exploit the possibilities of medicine.

Despite disillusionment with various possible means to cure and widespread knowledge about the outcome of AIDS, people have clung to hope and continued to pay what they could for anything that promised a cure even though this drained resources that


\(^2\) Colson, “The Father as Witch”.

otherwise might have been spent on food, clothing, or school fees for children. Unfortunately by the first years of the 21st century, when ARVs began to be available, many families had little left to pay for further treatment given all they had spent on the many who have been ill, sought a cure, and died.

In the years before ARVs became available, when the biomedical establishment and its allies, the international charitable agencies, were unable to offer hope to those infected, they expended their resources in fostering educational programmes on HIV/AIDS and its mode of transmission, the need to adopt safe sex through limiting the number of partners and the use of condoms made available through health centres, and more recently combating stigmatisation of those with HIV/AIDS and their close associates. Information was transmitted via radio and newspapers or through public meetings, often associated with the performance of dramatic skits featuring the need to avoid infection. Such programmes aimed at containing the epidemic by changing behaviour to prevent infection, disregarding evidence that by the late 1990s they were preaching to those who had already heard and did not want to listen to further messages assuring them that if they were already infected, as many suspected they might be, they were doomed to early death. In the circumstances, the informational programmes were more effective in adding to the anxieties of those who heard them than they were in altering behaviour with respect to sexual activity.

Gwembe people regarded sexual activity as a pleasure. Most men, whether single or married, thought it enjoyable to engage in affairs, and even married women might have lovers. With the emergence of townships around administrative centres, mines, fishing camps, and transit points from the 1960s on, some women had been drawn into prostitution serving both transients and village men. Condoms, if available, were unpopular, in part because they were said to lessen sexual satisfaction, but also because some churches preached that their use was both sinful and dangerous to health. Such preaching may have had greater impact than preaching about the sinfulness of sexual relations outside marriage.

The incidence of HIV infection began to fall nationally in the early 21st century, and this probably applies also within Gwembe Valley although we cannot demonstrate this and can only speculate about why it might be so. Some aspects of sexual behaviour did begin to change in Gwembe by the mid to late 1990s. It is doubtful how much the national campaigns were implicated in this and how much was due to the intimate knowledge Gwembe people had acquired through watching their fellows fall ill, become dependent, and die. In the late 1990s, the ritual purification of survivors from death pollution, which involved sexual intercourse, began to be altered or eliminated under pressure from surviving kin intent on protecting themselves from infection. This happened even before Gwembe chiefs were induced to ban the purification in the early 21st century. Increasingly, if AIDS was implicated in a death, surviving spouses were suspect of being infected even though they might appear to be healthy, and the inheritance of widows by matrikinsmen of the dead husband began to be avoided. In other circumstances, however, risks continued to be taken, even though by now people said openly that they did not want the burden of care for those who knowingly placed themselves at risk.¹

HIV/AIDS has carried stigma since the late 1980s, and stigmatisation may have increased as fear of infection has increased. While people know that AIDS is sexually transmitted, they also think it can be transmitted through contact with items used by one infected or through contact with the blood or other body fluids of those infected. Research teams in Southern Province have found people trying to distance themselves from those thought to be infected with HIV even before AIDS symptoms appear, and from those closely

associated with them.\textsuperscript{1} This means that those infected and their kin, even when they recognise an illness as AIDS related, usually persist in public denial. Few, so far, have wished to know their HIV status. This adds to the burden of anxiety attached to AIDS; for people live with the knowledge that they do not know all those among their associates who may be a danger to them.

Stigmatisation originally may have been influenced by knowledge that AIDS was stigmatised in Europe and the United States, standard-setters for many Zambians, especially the young educated elite,\textsuperscript{2} but the association of AIDS with illicit sexuality and death also resonated with existing concerns about contact with pollution. Among Tonga-speakers, illicit sexuality and death were seen as polluting. Those who came into contact with either could pass on the pollution if they were not properly cleansed. While carrying pollution, they were expected to observe various taboos to avoid transmitting the condition to others. With education and experience with antibiotics and other resources of biomedicine, fear of the old forms of pollution may have diminished or lapsed in the 1970s and early 1980s, only to be reinvigorated with the advance of AIDS.

The arrival of ARV therapy created new dilemmas and new ambivalences about learning of the HIV status of oneself and others. In the first place, the cost of treatment was prohibitive for most individuals and their families. Even at the subsidised price available at one Gwembe hospital by 2003, the cost of treatment for one person outran what most Zambian families could pay, and they might have a number of members with HIV. Drought years and crop failures continued in the early 21\textsuperscript{st} century, and most families were unable to buy food and depended on international aid. They had little or no surplus to spend on other things. And they were not alone in Zambia in being in this condition. By 2004, 73\% of the Zambian population was estimated to live below the poverty line, up from 68\% in 2000, while malnutrition was said to affect 53\% of the population.

Even in 2004, when international donors underwrote free ARV treatment for 100,000 Zambians infected with HIV, in a population with an estimated HIV incidence of 15.6\% among those in the 15 to 49 year age range,\textsuperscript{3} there was no rush to discover HIV status or apply to be enrolled. Those who knew about the availability of free treatment also knew that it was limited to a period of five years after which the cost would have to be met by individuals or by government. The treatment could have serious side effects. Enrolment for treatment was a public acknowledgment of HIV infection. And ARV treatment was a lifetime sentence rather than a cure.

Most people in Gwembe Valley in late 2004 probably knew little about the availability of free treatment. Those who did, including health workers, were not necessarily eager to take advantage of it even though they might know or suspect that they themselves had HIV. They knew it unlikely that government would or could pick up the tab after five years, or that they themselves could afford to do so, especially since salaries have not kept up with inflation and government is frequently in arrears in paying salaries of health workers, teachers, and other government employees. Some said cynically that only those in powerful positions or their kin would receive treatment.

\textsuperscript{3} \textit{HIV/AIDS in Zambia: Background, Projections, Impacts, Interventions} (Lusaka: Central Board of Health, 1999).
Living with AIDS and no ARVs

In 2004, Gwembe people continued to deal with HIV/AIDS much as they had done since knowledge of the condition first emerged: by denial if possible, by the use of biomedicine to cure opportunistic illnesses associated with AIDS when this is available, and/or by consulting African healers for a cure. The majority were likely also to search for underlying reasons why they themselves should be afflicted and find explanation in witchcraft, the anger of ancestors at the abandonment of old ways or failure to honour them, the invasion of new forms of spirits associated with the threatening international order, or, among Christians, God’s punishment for sin or the machinations of Satan. But given their current knowledge of diagnostic traits associated with AIDS and their knowledge of what these imply, it is difficult for people to deceive themselves about the nature of a case whatever they may say publicly.

In the 1990s, it became accepted knowledge among Gwembe people that AIDS related illnesses signalled certain death, and people became generally knowledgeable about typical symptoms and modes of transmission. They were then able to diagnose their fellows’ illnesses even though sufferers and their kin claimed a different origin. Denial was a refusal to accept a death sentence, as well as a continued claim to the use of resources in a search for a cure. At the same time, denial encouraged the stigmatisation associated with AIDS, for the nature of an illness became hidden knowledge not to be revealed to outsiders and therefore suspect. Since the early 1990s, as the incidence of HIV infection has risen and the number of those unable to work productively and in need of care has grown, the stigma has increased along with fear of AIDS.

Although there is widespread knowledge that HIV is spread through sexual intercourse, and also through the sharing of needles and razors, people also know that you cannot predict who will become infected among the many who have multiple sexual partners or have been exposed to injections (once a favourite form of treatment), and that there may be a long time elapse between infection and the appearance of the first symptoms. Few know their HIV status and many live with the knowledge that they may already be infected, and they do not know who among their fellows is infected. All this leads to a general sense of malaise, made no easier because of the difficult economic conditions under which people have lived since the late 1970s. Angry frightened people, whether they be patients, caregivers, or only worried about their own status, have turned to blaming others as the witches who direct the infection and by combating the witch think to rid the community of the disease. During the 1980s and 1990s, witch finding became endemic to Gwembe Valley as elsewhere in Zambia and throughout southern Africa. Payment to witchfinders was a further drain on scarce resources but was acceptable as a means to at least temporary reassurance.

Meantime, international agencies and local NGOs, equally helpless to cure the condition, stressed the need to change behaviour to prevent further spread of HIV, urged people not to stigmatise those with AIDS, and began to provide some support for the large number of orphans whose plight became a subject of international discussion. Some of the church based NGOs also provided a limited amount of support for the chronically ill. After 2000 they made available a limited supply of ARV drugs, at low cost or as from 2004 at no cost for a fraction of the infected population. What they could not do was make tolerable the circumstances under which those with AIDS are usually cared for or provide the kinds of resources in food and other comforts known to prolong the working life and delay the onslaught of AIDS among those already infected with HIV.1

HIV has spread at a time when economic conditions have undercut the resources needed to ease the impact of the epidemic upon those infected and those who must care for them. Government support for the health system was radically cut in the 1990s, partly due to

the demands of structural adjustment programmes which ignore basic needs. Since then, people have been expected to pay fees for previously free services at a time when medical supplies are frequently lacking and medical personnel is disappearing as doctors and nurses take jobs outside the country. Sanitation, including water supplies, is probably poorer than in 1980, leading among other things to outbreaks of cholera. Two of these struck Gwembe Valley in the 1990s. Unemployment and more frequent droughts mean that people have less money to buy food or to pay for health services. Many can’t obtain the nourishing food that delays the onslaught of AIDS infections and speeds recovery from them. Caretakers may lack such basic nursing supplies as soap, or clean clothing and bedding. They may be badly nourished, hungry, exhausted, and feel cut-off from others by the stigma that now attaches to those in close contact with AIDS patients. They know they are at risk, for hard-working hands frequently have abrasions and without protective covering come in contact with body fluids. Few outside agencies do anything to help the care-takers, who are mostly women who are also expected to produce much of the family food. They work knowing that they serve those who will inevitably die.

Even the phenomenal growth in membership of charismatic fundamentalist churches has provided little material relief, given the prevalence of stigmatisation and fear of stigmatisation if one is known to have HIV or be in close association with an AIDS patient. On the other hand, assurances that religious belief in itself can both cure and provide one with material success may ease the burden for some.

It says much for the moral fibre of Gwembe people, their fellow Zambians and others in infected regions of Africa that they have continued to provide care for the sick, have come together to bury the dead, and have tried to care for the children left behind. There has not been a total debacle. Somehow they have maintained a respect for their own moral integrity. Many have shown abundant compassion, not just for the moment but over the long months of illness of those for whom they have accepted responsibility. Once, one could have argued that they did this as part of a system of general reciprocity: as they cared for others, so they could expect to be cared for in their turn. But given the death of so many of the intermediate generation, leaving the old without caretakers in their turn, something other than reciprocity is at stake. I would argue that they conceive of themselves as responsible human beings, meeting their obligations as best they can, and so maintain their own self respect.

ARVs and hope

What is described above reflects the situation when I left Zambia in October 2004, when ARVs were just becoming available to the general public. Between then and my return in June 2006, a transformation had occurred as people observed the rapid recovery of those with advanced AIDS who had gone on ARVs. They saw and were convinced. For the first time many were willing to be tested for their HIV status, knowing that now a positive test was not the end of hope. Many who had AIDS, though certainly not the majority, were willing to announce publicly their status as they could point to restored health. AIDS counselling for those on ARVs spread, and so did the provision of special feeding arrangements for those who needed nutritional support. People reported unpleasant side effects as a result of taking ARVs, but found them endurable given their new ability to cope, and weight gains were approved rather than deprecated. Caregivers found their burden lightened as those who had needed care regained health and returned to work. Stigma attached to AIDS continued to exist, but lessened as people no longer lived in such fear of contamination. All this had a general effect as people saw the future
through less pessimistic eyes. People seemed to have new energy and new pleasure in life, though deaths continued and people continued to fall ill. The heroes of the hour were the Europeans who had found a remedy and the donors who supplied the drugs.

During the following year, optimism was maintained and people continued to ask that their HIV status be tested and to go on ARVs if this was appropriate. But those who work in HIV programmes and serve AIDS patients are concerned about what will happen when those now under treatment need new levels of medication, for which so far there are, as of mid-2006, no financial provision.

Responses to the AIDS epidemic over the years have reflected a multitude of factors including knowledge of outcomes, sources of infection, and possibilities of treatment. Responses can be expected to continue to shift as conditions change and so will the moral implications of HIV for those infected, those associated with them, and the wider society which must sustain them.
Part Four

Facing the Challenge of HIV/AIDS
Choosing Between Life and Death:
Rationing of Health Care During the AIDS Epidemic in South Africa

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In the year 2000, our book, *AIDS Doctors: Voices From the Epidemic*, was published.¹ By that time, the relative therapeutic impotence of the first fifteen years of the epidemic, at least in North America and Europe, had drawn to a close as powerful antiretrovirals became the standard of care. *AIDS Doctors* was an oral history that sought to capture an important perspective on the course of the HIV outbreak in the United States before it was lost. It aimed to preserve the memory of a long and dreadful period for those who might come to look back, uncomprehendingly, on what it was to be a doctor in that country, caring for those afflicted by AIDS. Our central goal was not to gather new facts, although we did so. It was rather to use oral narrative to write the epidemic’s history, to tap each doctor’s subjective sense of events and to elicit the meaning that he or she found in them. Our approach allowed doctors to address the professional, personal, political and ethical issues the epidemic raised for them. The result was a collective biography, a two-decades-long story of the experience of a minority of doctors who committed themselves to treating patients with a new, stigmatized disease.

2000 was also the year that the International AIDS meeting was held in Durban, South Africa. The light it shown on the epidemic in that country was shattering. Although there had been an earlier outbreak of AIDS in the gay communities of South Africa, from the mid to late 1990s a massive heterosexual epidemic had taken hold. This was a bitter irony, since it was in 1994 that South Africa had finally liberated itself from apartheid. Worse, the epidemic revealed the social and political fault lines of the post-apartheid state. We came to believe, at that moment, that a new oral history project, one that captured the full experiences of both doctors *and* nurses working within the epidemic in South Africa was crucial.

As we had in the United States, we identified a number of key informants, primarily South African, who provided us with lists of doctors and nurses who had been working for some years with patients infected with the HIV. Those clinicians, in turn, gave us additional contacts. In all, we came to interview close to ninety doctors and nurses across South Africa, from urban centers like Johannesburg, Cape Town, Durban and Pietermaritzburg and rural clinics in places like Tugela Ferry and Lusikisiki.

Over the past decade, a substantial literature on the South African AIDS epidemic has begun to emerge, largely written by epidemiologists like Salim and Quarraisha Abdool Karim, social scientists like Alan Whiteside, Nicoli Nattrass, Mary Crewe, Helen Schneider, Virginia van der Vliet, Loveday Penn-Kekana, and Charles Becker and his colleagues. A few, like Philippe Denis, have tapped oral history techniques. None, however, have had as his or her central purpose to write the history of the epidemic from the perspective of health workers at the coal face.

Our interviews were guided by a series of broad questions that sought to trace the experiences of each person we interviewed, but remained open to areas of inquiry that we might not have anticipated. Perhaps the most distinguishing feature of the interviews conducted in the United States was the recognition of the need to remain attentive to the political context within which the AIDS epidemic was unfolding. In South Africa that social matrix was even more critical, particularly the existence of vast inequalities in access to health, the subtle and not-so-subtle legacies of the apartheid regime, and the scarcities that shaped so much of the South African health care system.


Rationing of medical resources, therapeutic interventions, and life itself is a fact of life in South Africa. Reflecting both resignation and a pragmatic determination in the face of scarcity, a young doctor working in a remote rural area of KwaZulu-Natal said,

I have always worked in a framework where I assume that there aren’t enough resources. For me it has always been ok, how can we find a solution, rather than becoming indignant.

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The reality that defined his work was shaped by the current lack of resources and the legacy of apartheid. The health care system in South Africa is mixed, consisting of a private and public sector. Physicians in the private sector serve the needs of the privileged, defined in terms of relative and absolute advantage. Those employed in the under funded public sector treat the poorest, medically neediest population. Ten years into the post-apartheid state, class and race still define who shall be cared for, and influence who shall live and who shall die.

While those providing medical care in many less developed nations compare their impoverished health systems to what exists in wealthier countries in the global economy, in South Africa such radical differences exist within the confines of a single society, usually within the same city. In a nation formally committed to razing apartheid’s institutional legacy and creating a social democracy after years of bitter liberation struggle, these enduring differences have become inequities gnawing at the foundations of the new order.

In this paper we examine the rationing of health care and life itself for those with HIV in South Africa, a nation with more than 4 million infected individuals. We explore this issue through the eyes of doctors and nurses who have been involved in the care of infants, children, women and men burdened by AIDS and AIDS-related conditions. This account is based on more than eighty-five interviews conducted in South Africa between January 2003 and January 2004. Those we interviewed were identified by AIDS experts in South Africa or through “snowballing” techniques. They were Black, white and Indian. They worked in hospitals, vast institutions like Chris Hani Baragwanath Hospital that has always served Blacks living in Soweto, or integrated institutions that had historically served only whites. A number tended patients in former mission hospitals that retain the religious ethos of their provenance. There were private practitioners whose rooms were as elegant as those of doctors in Europe or America. Others provided care in spare, cramped quarters. Some clinicians we interviewed treated patients with substantial private resources or with medical insurance, some the unemployed and impoverished. A number of doctors and nurses we spoke with were employed by AngloGold, a mining conglomerate. Our interviews, which lasted two to three hours, used a set of open-ended questions to which individually tailored queries were added. Interviewees were asked to be as frank as possible and were promised the opportunity to review, amend and approve their transcripts before they would be used in a way that could serve to identify them.

I.

The AIDS epidemic in South Africa both highlights and magnifies the clinical and moral problems raised by medical rationing. When resources are limited, either because of policy decisions or absolute scarcity, who should be offered care? What moral judgments, clinical assumptions, medical evidence inform such decisions? Should the rules of rationing be explicit or implicit? Should such norms be applied in an invariant “objective” fashion or with a degree of flexibility? Should rationing be blind to the exigencies of patient differences or should the claims of real people bend the rules? Such questions had to be addressed as an unparalleled epidemic threat exacerbated already difficult conditions.

One of our informants portrayed the growing chaos as a rising tide of patients suffering from AIDS sought admission to a public hospital in Durban in the late 1990s:

People used to be coming in on stretchers from all over the outlying areas absolutely sick, dehydrated, vomiting, hardly able to breathe, and their entire communities used to come along with them. APlease help this person; do something.@ And there was no mechanism in that hospital to
take these patients in, to sort them out medically, to equip them with the knowledge and the means to go back home and take care of themselves. The hospital was so overwhelmed with the numbers of these patients that the basic minimum was done and they were asked to go back home; that was a terrible thing.

A doctor at Chris Hani Hospital described how patients had begun negotiating for hospital beds:

The fact that you are HIV infected now is that you can hardly even get into this hospital. You get turned away at casualty. When it started, people would spend a lot of time investigating HIV infected people. There would be a time when there would still be admission to the ward, but they wouldn’t get the best care. Now there is a time when you can’t even get them into the hospital.

However many people with AIDS were turned away, the sheer number applying meant the wards began to fill with such patients. In fact, careful analyses have suggested that despite increasingly crowded conditions, with “floor beds”—blankets under beds—to accommodate the overflow, it was those with HIV who were pushing out other patients.

Having gained admission, AIDS patients encountered limited treatment, often bordering on neglect. Implicit or explicit beliefs that people with HIV-related conditions represented a sink hole informed such behavior. In the words of one of our doctors, the common stance was, AWhy treat these patients? They are going to die anyw ay.@ While many doctors and nurses spoke with bitterness of the refusal of colleagues to provide particular medical interventions to patients solely because they were infected with HIV, even the most sympathetic could be filled with doubt. As a physician at King Edward Hospital in Durban recalled:

The patients would come in with tuberculosis (TB) [first occurrence of TB…] and then you would treat it. They would come in with PCP (to develop…: Pneumocystis carinii…) and we’d treat it. But then they would develop cryptococcal meningitis; we tried to treat it and 70% never left the hospital alive. You watched your patients die. And then, for a year or two, I went through this phase where I said, “Is it worthwhile treating these patients, because they are going to die in any case.” And we felt we were beginning to deprive the health care system of resources; in other words, pouring it down the hole and getting nothing in return. And I took the view that patients with advanced AIDS shouldn’t be treated. They should be offered hospice care; and those who were pre-terminal should be sedated because it’s not nice to see them suffer.

Indeed, gripped by a sense of the futility of treating AIDS, physicians embraced the argument that a fair and just health care system required the husbanding of resources. A failure to ration care meant that others who might benefit would be deprived of life saving treatment. The systematic exclusion of people with HIV from intensive care units at many public hospitals seemed a reasonable choice, given the alternatives. There were precedents. One pediatrician viewed the restriction of care to people with HIV through the lens of his neonatal experience:

There was an issue of premature and low-term babies. I was dealing with this on a daily basis. AIDS wasn’t very different. I was very straightforward with parents, basically saying we have limited resources, twelve ICU beds; mother, if the baby doesn’t improve, we are going to withdraw care. That was my own method of dealing with it. It wasn’t the matter of should we or shouldn’t we take your baby off the ventilator…or shouldn’t we send your child with HIV to the ICU. It was a matter of fact. We are doing this. I think most parents will accept that because in the kind of environment we worked in, the doctor was God.
A doctor in a public hospital in Cape Town defended the exclusion of some AIDS patients from the ICU as long as that policy was categorical and supported by clinical data:

Our intensive care unit has now made an explicit policy that they will not admit people with [pneumocystis] pneumonia into the ICU (Intensive Care Unit). I think that’s not unreasonable given that they have very limited facilities. They had looked at all the mortality for other diseases, around 20%. They’d looked at their own pneumocystis experience, and it’s around 60%. That’s not a good use of resources. So they have decided to exclude that group of patients, and I don’t have a problem with that, as long as it’s explicit. I quite like that very recent trend in rationing we now have. People are saying they have done the same thing for head injuries in this hospital.

But that same physician admitted that his own hospital provided expensive, technically demanding, high risk therapies to patients with diseases other than AIDS; AIDS was, in fact, perceived as different:

AIDS, it’s not like other diseases. This hospital does cardiac, liver, renal, bone marrow transplants. We use almost all the drugs that you would in the United States to prevent rejection. We do dialysis. So expensive therapies are available here, but not for HIV. So there’s that injustice; that is very hard.

Restriction on access to the ICU could nevertheless coalesce into rigidity, applied even once clinical justification no longer prevailed. What was earlier taken as just could then become unreasonable, an act of invidious discrimination. A doctor working at Chris Hani Hospital in Soweto recalled:

We managed to get some kids onto anti-retroviral therapy. These kids were on triple therapy and had reasonable clinical prospects. But on occasion they would require ICU. And I would phone the head of the ICU and say this child should go into the ICU because this child was on triple therapy and had a good prognosis. And they would not let the kid in because the kid was HIV infected.

Although there is evidence of explicit decisions to ration care, buttressed by reasoned arguments and data, in most instances restrictions on access to care seemed to emerge organically, without careful thought, most often a consequence of structural forces, the lack of resources that affects much of South Africa’s public medical sector. As one pediatrician in a public hospital noted:

I think there has certainly been evidence that care has been rationed to HIV positive children, as it is to adults. Some of our colleagues did present figures that showed that the average stay of an HIV positive child is less. Certainly HIV positive children are getting less care. They are being discharged earlier because people feel that there is nothing that they can do. I don’t think it’s been a conscious policy decision; it’s just been the way that people cope with the numbers and the reality of a busy African general hospital. I think it’s the wrong decision. But the solution to the problem is not going to come from individual doctors or individual hospitals. It’s going to come from a policy that provides comprehensive AIDS care as it should be provided.

Many who were troubled by the assumptions behind rationing health care for HIV infected patients, inveighed against the ignorance of their colleagues who equated AIDS with death. Fatalism, they believed, whether given voice in a language of despair or high toned stoicism, was unwarranted. Speaking of the care of AIDS patients, one private physician recounted:
Our colleagues say, “Oh, no, there’s nothing I can do for you.” I know of a circuit HIV ‘expert’. The brother of a patient of mine is being treated by this man. She phoned him up to say, “He’s getting very thin. I’m worried about it.” And the ‘expert’ said, “Well, what do you expect?” She asked, “Is there nothing we can do?” “Why bother doing anything? He’s going to die one of these days anyhow.” I was absolutely horrified. I had her bring him [to me] because that mentality is absolute bullshit and I’m not going to accept it.

Thus the impulse to deny care might reflect inadequate knowledge about how opportunistic infections could be treated and about the prognosis of patients who receive appropriate care. Strikingly, such ignorance has characterized not only those who had finished their medical training before AIDS emerged as a defining issue for the health care system of South Africa, but also those who completed their medical education well into the epidemic’s development. Speaking of the students who came to Chris Hani Baragwarmath Hospital as late as 2003, a physician noted:

The level of knowledge [about AIDS] I find in medical students who have been at medical school for four, five, six years, because that’s when we see them, is absolutely appalling. I don’t think they are actually learning anything, and that is very frightening. Again, it’s partly been an attitude within the medical department and the internists that they have no drugs, they can do nothing; this is getting in the way of what real medicine should be like. And, unfortunately, medical students are taking that on board. Doctors who graduated in the last five years know very, very little about HIV.

As a consequence of such therapeutic nihilism, fatalism and growing exhaustion before the waves of HIV cases, doctors often made presumptive diagnoses that justified inaction and deprived patients of life-extending, medically appropriate services. One of our informants spoke of a case in one of her wards:

There was a child whose encephalopathy they just attributed to HIV. And I was outraged. I said, “But you haven’t investigated this child. This child could have TB meningitis; it could have anything. Why haven’t you done a lumbar puncture on this child?” So what happened was that people stopped investigating children with HIV; they wouldn’t bother making sure that they had covered all the different angles.

Most telling about the attitudes that pervaded public hospitals in the mid to late 1990s was the resistance on the part of many hospital administrators to the establishment of special clinics designed to meet the needs of those with AIDS. They looked upon AIDS with oceanic indifference. Speaking of two public hospitals in Pietermaritzberg, a doctor asked:

What was the activity for the problem of HIV? There was nothing, absolutely nothing. There was no HIV clinic in Grey’s Hospital [which had historically been a white hospital], at Edendale [which had served Blacks during the apartheid years]. There was a Rumanian lady who tried to do something, something with nothing. Nobody was supporting her. Nobody was giving her help. The venue she was working in was terrible. Eventually she got another place which was even worse. All that she was doing was not respected.

At Chris Hani Hospital, the pediatrician who established a clinic for children with HIV and their mothers was told when she left on sabbatical that the clinic would be closed until she returned. No administrator or clinician would step forward to assume her responsibilities.
How did the limits on care affect those who had not sought to turn their backs on AIDS? Those who stayed in a public sector so overwhelmed by the epidemic or who in the context of private practice developed large AIDS caseloads? For some the only option was an emotional distancing that made the suffering of their patients easier to endure. Working in a rural hospital, a doctor, acutely aware of the epidemic’s traumatic impact on him, recounted:

What I find quite difficult is that so much death is anonymous. The people come in. They are moribund and die the next day. Families bring people in; they have got severe thrush and they are emaciated, they have got diarrhea and like three or four days later they die…It’s a flood difficult to engage with …It blunts us to treating people very carefully. You almost don’t want to know. You don’t want to engage with it because engaging with it makes you tired, makes you exhausted. You have heard it so many times and it’s not interesting anymore or stimulating. You don’t want to know about another person’s pain. So often two o’clock in the morning, when you are tired, they would come in. I mean, this person has been like this for how long and now you come in at two in the morning? Why are you wasting my time? It becomes very difficult then to start to say “So what does it feel like?” Actually, I don’t care. I don’t give a fuck. It gets too much. You don’t want to engage with it; it’s not important.

Another fact that makes such distancing possible, often precluding intimate contact with patients, is the barrier of language. We were struck by how rare it was for white and Indian doctors to speak anything more than a few words of any African language. They frequently told us, “It’s just too difficult,” “I’m not a linguist, I’ve tried,” “I should, but I don’t have the time.” Although apologetic, doctors seemed relatively untroubled by the fact that they couldn’t develop a direct relationship with those they treated, but depended upon a third party—a nurse, a clerk—to communicate with their patients. That this was so, even among the most committed of doctors, must be seen as a legacy of apartheid.

The inability to share a common tongue between doctor and patient certainly makes implicit and explicit rationing psychologically easier. The patient remains “the other.” One of our doctors was especially sensitive to the issue, having forced himself to learn Zulu:

I wanted to speak Zulu because I wanted to know what was being said. Once I started to understand Zulu, I realized that there’s just mountains that gets lost in translation. And for me it’s one of these things that prevents me from blunting; it helps me to engage with the person. I think what’s quite interesting is that a lot of patients want to see me because I speak Zulu, especially if I’ve seen patients before. They often want to come back to me.

Understanding Zulu was instrumental in moving one influential Indian doctor in Durban from a cool and reasoned position of therapeutic nihilism and resource rationing to a defense of active clinical intervention:

What I began to see happening around me was a sense of hopelessness amongst the medical staff. In the minds of the junior doctors, they were beginning to question, what the hell am I doing here? If 80% of your patients have AIDS and you can’t do anything, what am I as a doctor? What really turned me around was one incident, where I was doing rounds with my team. We came to one patient. We discussed his cardiac problem, discussed treatment, spoke to the patient. I saw the next patient and then told the person, no to that patient. I knew he had advanced AIDS; there is nothing you could do, and we skipped him. I understand Zulu, so that patient told the patient next door to him, “I wonder why the doctors don’t want to see me today. I think I am going to die.” I heard this and froze in my tracks. I suddenly realized that the patient is right; this is the message I sent him. In my heart I knew that was the reality, but what I took away from him was his hope. I immediately realized that was wrong. I had to just stop there and greet him; it wouldn’t have taken
long. I came to my office and I sat down there, and I think I must have shed a tear or two, and I realized that if this is what I am doing as a doctor, then I am in the wrong place. I must either leave the system or do something about it. And so increasingly I started getting involved and sort of looked around to see what opportunities there are for anti-retroviral treatment.

II.

In 1994 when the HIV epidemic began its catastrophic escalation in South Africa, but when the number of clinical cases was still relatively small, the global picture with regard to anti-retroviral therapy was grim. The Concorde trial in Europe had demonstrated that AZT, the first anti-retroviral drug used in the AIDS epidemic, was relatively ineffective. A common bond united the richest and poorest nations. In neither was it possible to combat the underlying course of the cascade of disease that afflicted people with AIDS. But in 1995 that began to change. The first reports about a new class of drugs – the protease inhibitors – indicated remarkable efficacy. By 1996 an air of triumphalism characterized the International AIDS Meeting in Vancouver, Canada. Triple combination therapy was shown to reduce viral loads to undetectable levels. Patients were snatched back from the edge of death. But these therapies were extraordinarily costly. And thus did the global divide begin to define the AIDS pandemic. In rich nations, AIDS was increasingly viewed as a manageable, chronic, if ultimately still fatal disease. In the world’s poorest nations, where the epidemic dwarfed the burden in the industrialized world, the therapies were all but inaccessible. Rationing by ability to pay came to define the global world of AIDS.11

In South Africa, the cost of the new drugs, of HAART – Highly Active Anti-retroviral Therapy – seemed utterly out of reach. But to some private practitioners, especially those who had been involved in the care of gay men in the early and now all but forgotten first South African AIDS epidemic in the mid 1980s, it was possible to prescribe the new treatments. Within private sector medicine, some small number of patients could thus begin to reap the benefits of the new scientific achievements. And so in South Africa, the gulf that had always characterized the privileged and the masses was given a new expression. Those who could afford treatment would live. Those who could not would die.

Even as the price of drugs began to decline at the end of the 20th century and in the first years of the 21st – as a result of political pressure on the pharmaceutical industry and as a consequence of competition from the generic manufacturers – and as private medical insurance began to cover the cost of anti-retrovirals, those who could afford the life saving treatment remained small. Within private practices and in hospital settings, some could purchase drug treatment, most could not. Rationing medications by the ability to pay became the norm in South Africa, especially since the government of President Thabo Mbeki has refused until recently to fund anti-retroviral treatment in the public sector. Private physicians were forced into the uncomfortable position of having to gauge what their patients could buy and into the morally difficult role of having to limit what they could offer. One of our doctors, a Christian woman working in a historically Christian hospital, described her sense of sorrow and paralysis:

11 See the conclusion chapter and the synthesis by Jean-Pierre Dozon : “From the social and cultural appropriations of AIDS to necessary political appropriations : some elements towards a synthesis”, 689 & ss, in Becker Charles, Dozon Jean-Pierre, Obbo Christine, Touré Moriba (éds), Vivre et penser le sida en Afrique / Experiencing and understanding AIDS in Africa).
It is horrible. It is very hard when you know that there are people that do get good care. There are many gaps in care because of cost factors. Your heart breaks sometimes when you know if they had anti-retrovirals they could carry on bringing up their children. They could carry on, and you know they are not going to. It is heartbreaking when you know that there is something that can be done, and you actually can’t do it.

The most compassionate doctors were paradoxically forced to spend time teasing out financial information, feeling out what patients could afford without adding further to their emotional burdens. Working in a public hospital in Pietermaritzburg, where some patients had the ability to draw on personal or family resources, one doctor noted:

It would be possible to ask a sister to have a talk with the patient explaining the anti-retroviral drug and the cost. But it has not been my approach. When we see a patient for the first and second time, we have a questionnaire, so we have some information about the job they are doing, whether they are working, do they have some income, who’s taking care of them financially. We also look at how they’re dressed, and so on. When the feeling from the information is positive, then I start to ask what the maximum amount of money would be that they could afford per month for treatment. Often they say it will have to be a small amount, because they cannot imagine what it will cost. When they have said that amount, I try to increase it to see if it would be possible. We try to find if the patient will be able to say yes or no.

Under these circumstances, plumbing a patient’s finances and those of his or her family could be torturous for any doctor or patient:

It is very difficult. You don’t want to miss someone who could afford ARVs; and you do not know if there is someone who might have an uncle, or if the family all got together they might be able to rustle up the money. So it doesn’t feel right for people not to know in case they can afford it. But to tell someone there is something that you can do, I always say in the beginning it is very expensive and most people can’t afford it; that is how I start. So at the very beginning they don’t have this hope, this total hope. But this girl, we talked about it, and she said she cannot afford it, and she cried. You sit there and can just cry with them really, because there is nothing I can really do.

For some the encounter with inequity was simply a fact of life. They could do little to resolve the problem within the limits of the clinical context. The result could be the equivalent of a moral shrug of the shoulders. Others took refuge in their Christian faith, shepherding each patient through his or her illness:

It is very hard to have people coming in and you know that this is their chance and they cannot afford it. You just have to take each person as they come. The whole person sitting with you in that room is the person you are concentrating on, giving a handle on what you can do that’s going to help them best in the situation they’re in. You can’t be comparing all the time. When the people can afford anti-retrovirals, and they come back a month later, and they put on five kilograms, and they are grinning from ear to ear, it’s really exciting and you rejoice with them. But when the next person comes in, and there is nothing that you can do because no one can afford it, then you have to just work out what’s best for that person. If they need to go to a hospice, organize a hospice. If they need their family to be trained for home care, do that. You have to take each person as an individual and do the best you can under the circumstances.

In the end, taking refuge in her belief in an after life, this committed physician was able to say “life is not everything.”
III.

For those who resisted such resignation and for whom the limits imposed by the cost of drugs were intolerable, one alternative to rationing by ability to pay was to undertake clinical trials that could provide at least some of their patients with access to anti-retrovirals. Said one clinical researcher in Cape Town “We try to squeeze [our patients] into clinical trials.”

For international pharmaceutical firms, poor, drug-naïve South Africans represented an ideal population for research. As one doctor observed, “We had tons and tons of patients who had never smelt ART, so that we could get the numbers up very fast, and we were a cheap place to do research.”

Such trials benefited both patients and doctors:

I have been involved in a number of drug trials. On the plus side, they enabled us to use the drugs on public sector patients, which we had never been able to do. We treated several hundred patients. It was great for our patients to have the disease turned around instead of going downhill all the time. There was also money that came in, which was good for research. And also some money came into our hands as well. It was seemingly on that sort of level, win/win. Win for the patients, win for us, and win for research. Everybody was happy.

Some doctors, stepping away from hands-on practice, ironically became more successful clinicians, more helpful to those in desperate need of treatment, by becoming investigators. As one doctor in Soweto’s Chris Hani Hospital put it, “We became more researchers than treaters; so we were in a better position, because we could get children into clinical trials.” Those trials stood as a welcome contrast to the lugubrious grind of AIDS care. As one physician working in Cape Town remembered:

It was a wonderful sort of revolutionary place because you know your patients could come there and get better. That was the exciting thing. All those years at the PM clinic, which stood for “afternoon clinic” because it was used for the HIV clinic (until somebody pointed out it could be “post-mortem”), we were following up people’s CD4s that were just going down the tube. But wherever we could, we tried to enter our patients into clinical drug trials. So I had the pleasure of watching a whole cadre of special patients that I loved actually blooming on drug trials.

Some people with HIV learned that anti-retroviral therapy could mean the difference between life and death. They began to question the manner in which research subjects were identified and asserted that equity required that they be included among those who would have a chance. A doctor in Soweto recalled:

A woman came to me and said, “How come if you are white and gay and live in Johannesburg you can get into a treatment trial; how come you don’t get us into these treatment trials?” So in 1996, we started approaching drug companies, and at first no one would touch us because these were Black women. They were illiterates. They lived in shacks. They were not going to take their medicine. They were going to fall out of studies. So nobody would give to us. Luckily, there was a woman who was the medical director of Pharmacy Upjohn in South Africa who was at medical school with us and decided to cut us some slack, and said I will give you one study. In three months, we were the second highest in enrollment in the world, and our results were good. Women, if they are supported, they are going to take their medicines.
But however inclusive, by its very definition research must exclude. Some will be drawn from the pool, others will be left to the downward spiral of HIV disease. Under such circumstances, where making a selection is, in effect, “playing God,” how are patients to be chosen? Even when pharmaceutical companies developed the criteria, there were more candidates than slots. One physician in Durban described the selection process for a trial with 30 participants. In this instance, the rationing principle was first come, first served:

There was a very careful interview process to explain what the story was, and the story was CD4 counts and viral loads; so that was taken into account. That was hard, because there are always more people that would love to be in the trials than there are spaces. It was very much the first people who were accepted who were in the trial; and when the numbers were closed, then that was as far as it went.

In addition to clinical criteria, a litany of limiting factors might define eligibility. In Khayelitsha, a township outside Cape Town, the Médecins sans frontières (MSF) clinics that sought to provide anti-retrovirals under the rubric of “operational research” (thereby eluding the government’s strictures on ARV treatment in the public sector) relied on committees to undertake the task of selection. In a neighboring community, Guguletu, in another operational research project, a team of health workers weighed a hefty set of selection criteria before doing “the Solomon thing”:

People have to have a CD4 count of under 400 or an AIDS-defining illness. They have to live within Guguletu, Nyanga district. They have to be attending one of the clinics in the district for at least 6 months. They have to disclose to at least one person in the community. They obviously have to be willing to take part in our program, which means attending all our meetings. And they have to be willing to have a therapeutic counselor. They also have to be mobile and able to get to the clinic themselves.

Despite these extensive criteria of judgment -- attempts to reduce the burden of “playing God” by making the act of selection both impersonal and objective -- the force of an individual personality, of all-too-human emotion, could break through the constraints erected against impulse and favoritism:

I had a young woman who had quite severe pulmonary disease with pulmonary hypertension. She was quite breathless, and the question was, is this the reason to give her drug to somebody else who will live longer, because she has another illness which may kill her before the HIV does? So we had agreed on every other front; she was treatment ready; she was psychologically sound; she filled all the other criteria. But what about her physical state? And she must have gotten wind that she was hanging in the balance. As I walked into the clinic, she did some star jumps and jumped up and down and moved her arms, and she said, “See doc, I am fine; I am absolutely fine.” There was just no way that I could actually say she mustn’t get the drug. I mean, there are just times when somebody’s needs and psychology, and the fact that they are human beings, just overwhelms every sense of better judgment. I didn’t even examine her. I walked straight out and said she has to go onto treatment. I can’t refuse.

But it was also necessary to determine, within the limits of resources, how severity of need should affect the prospect of being selected. The instinct to rely on the rationing principle -- give first to those in greatest need -- had to confront the claims of institutional survival:
We had to make sure that they are not too sick. Too sick patients have a very high mortality, and that is tough on the program. It feeds the propaganda that drugs are toxic. It’s very time consuming for primary health care clinic expertise. It’s tough on resources.

For all the joy of seeing patients flourish once on ARVs, either through clinical trials or “operational research,” doctors were reminded of those who had been excluded. In a society where the Government refused to offer anti-retrovirals to those who might benefit, the consequences were dire:

I appreciate the Minister of Health’s talk, sort of saying, “Bear with us, we need partnerships; we are doing what we can.” The all-pervading thought going through my mind is, I just think of all the people, and I knew many of them, where we just watch them get more ill and eventually die, and have nothing to offer them other than, I think, pretty good opportunistic infection care. And at least we can offer them that; but having by default to visit people in their homes and organize palliative care, when you could see other people getting better and doing well, I think the inequality and injustice of it is particularly a horror.

In both Khayelitsha and Guguletu, the research programmes were designed with no endpoint. Treatment would continue indefinitely, as long as resources held out. But that was not typically the case in clinical trials, which, by definition, would conclude once the efficacy of a given drug had been assessed. In South Africa, where clinical trials were the only source of ARVs for many in the public sector, it was inevitable that the question of what would happen to research subjects when the trial ended began to surface. Did the principle of justice necessitate the provision of effective treatment indefinitely? Was it the moral obligation of the pharmaceutical firm to shoulder such costs? What duty did researchers have? Should they press for continued and unlimited access to effective pharmaceuticals beyond the trial’s end? Given these concerns, some ethics committees refused to approve trials in which subjects would not be guaranteed post–study access to effective drugs:

The first time we submitted this trial to the ethics committee, they turned it down because they said the company promised to give us 2 years afterwards and that wasn’t enough. They wanted lifelong. We told the women in our support group, and the women said, “No, we want to meet this ethics committee.” And those women sat there and said, “I’m HIV infected and I am dying. I can be on this trial for 2 years, and if I do well, I’ve got another 2 years access; it’s 4 years, and you are turning this down, so you are killing me.” There was this ethics committee of white, middle aged men who looked at these women and for the first time were confronted with these kinds of issues. And in fact, they then approved the study.

Moved by the desperation of their patients, clinicians who took their fiduciary responsibilities seriously also felt a distinct ethical queasiness.

Of course, the real ethical issues are what do you do at the end of the study, and what do you do for people who are failing therapy. If you are failing therapy in the States, you would go onto alternative therapy that may work. Here there was no alternative. Some of the trials, at the end of the trial, therapy was finished. Others would say, if you have treatment success you can continue. They would define success very strictly. So somebody is clinically benefiting, gaining weight, looking great, but they aren’t under 50 copies per milliliter; they had to quit at the end of the study. That put us in a very difficult position ethically. Very, very difficult position. It didn’t feel clean.

The struggle over post-trial access was embedded in a larger political context. President Thabo Mbeki had, by the end of the 1990s, begun what seemed to every doctor we interviewed...
Facing the Challenge of HIV/AIDS

an utterly inexplicable romance with the discredited Peter Duesberg, the American scientist who rejected the thesis that HIV caused AIDS. Those who accepted his perspective viewed anti-retrovirals as dangerously toxic. Physicians who promoted their use were suspected of being agents of the pharmaceutical industry, forsaking their loyalty to nation and people.

Indeed as clinicians pressed to widen access to ARVs – only universal access could obviate the need for rationing—in alliance with the grassroots Treatment Action Campaign, the Government responded with fury. Those who had provided anti-retrovirals were denounced in a broadside, *Castro Hlongwane, Caravans, Cats, Geese, Foot and Mouth and Statistics*, some have traced to the office of the President. It declared, “We do not know how many of our people have died, as those at Chris Hani Baragwarnath Hospital conducted experiments on our people or ‘treated’ them relying on dangerous results of clinical trials.” Referring to a clinical researcher who had openly challenged government’s position, the document went on:

“[Who] must be held accountable how has this been exposed?”
Since Chris Hani Baragwarnath Hospital must be held accountable how has this been expressed?

“We must …know that we have succeeded to produce geese among us that have been fattened by those who hold us in contempt.

Those appalled by the toll of disease increasingly came to believe that the failure of the government to act, to broaden treatment access, even if universal access would take years to achieve, represented a grave moral and political error. The consequence was avoidable suffering, preventable death. It was Government that was imposing conditions that made rationing, rationing by clinical trial, operational research, or ability to pay the dominant rule of treatment access. The Government’s failure was all the more inexplicable, given the legacy of apartheid and the struggle to overcome the years of racist rule.

A physician working at Chris Hani Hospital thus declared:

This is the antithesis of everything that the struggle was about. We were fighting for democracy, for people’s rights. We were allowing our own government, a democratic government, to basically allow 50,000 babies die each year. And so it went to the core of my whole philosophy of life. I think history will view the actions of this government as regards HIV/AIDS very seriously. I am still a supporter of the ANC, but this is genocide.

A colleague at Chris Hani Hospital drew the only possible conclusion, given the invocation of genocide:

They are going to have to go on trial. They are guilty of genocide. They are guilty of human rights atrocities from Mbeki down to the Department of Health…We are looking at people dying, and we can intervene, and all that is happening is obstruction, left, right and centre.

For black doctors who felt similar outrage it was not as easy to invoke the language of trials and genocide against the ANC that had led the struggle against apartheid. One physician who had been trained as a doctor under the sponsorship of the ANC, and who had lived in exile,
said that the ANC “was like a home.” There was no possibility of struggling for change in AIDS policy with a political formation outside the party.

In August 2003, under intense pressure, the Government announced that the Cabinet had approved a plan to roll out anti-retrovirals treatment over a period of five years. Seventy-seven sites were to be selected throughout the nation to implement treatment in the first year. A commitment to geographical equity dictated that at least one site exist in each of the nation’s health districts. The long awaited roll out will not, however, put an end to rationing. Although the plan assumed that 400,000 individuals would develop AIDS-defining illnesses in 2004, only 53,000 would be placed on treatment in 2003/04. In the program’s 2nd year, the cumulative number of treated cases would rise to 188,000. Only by 2008/9 would the program reach its target of just under 1.5 million treated cases. In the interim those not covered by the ever expanding treatment network will get sick; untold numbers will die. For the untreated, their families and the communities from which they come, the promise of universal care and the end to the rationing life will seem a very distant promise, one that, if reached, may simply be too late. Time in the interregnum will have served as the ultimate standard of rationing. In the words of one of our doctors, heading a rural hospital not selected for the roll out, at least not yet,

It feels strange to see the new possibilities so close… And yet, so far to go.
Facing the Challenge of HIV/AIDS
AIDS in Burundi and South Africa: 
A Day-To-Day Experience

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HIV Clinics, Greys and Edendale Hospitals, Pietermaritzburg, South Africa

Introduction

Twenty-four years ago the first cases of AIDS were identified. From a small scale epidemic of little interest other than intellectual and medical, initially limited to marginal groups in developed countries, such as homosexuals and drug addicts, Haitians and later non-marginal blacks in Central Africa, we have progressed to a pandemic involving scores of millions of infected subjects, fifteen million deaths, millions of orphans the majority of whom live in Africa and an interminable process of family dramas.

The following article is not a product of research. It is rather a testimony based on memories stretching over the years. It calls to mind how clinicians, foreign and national, in daily contact with patients affected with AIDS, lived through the different phases of this unparalleled medical disaster, first in Burundi (1984-1994), then in the South African province of KwaZulu-Natal (1996-2004). The author accepts sole responsibility for the remarks made in this article.¹


Discovery of the existence of AIDS

In 1983-84 strange occurrences suggested to clinicians that AIDS, which had recently been described in the United States, also existed in Burundi: increase in cases of cryptococcal meningitis, candidal esophagitis, Kaposi’s sarcoma spread at a furious rate, and polyadenopathies syndrome with disturbing histological images and a rapid relapse of tuberculosis after correct treatment.

¹ I thank my colleagues whose names follow. Together we did our best to contribute to the fight against AIDS.
- in Burundi, L E Petat, pharmacist-biologist; doctors J Perrin (Coopération médicale française); B Standaert, M de Maedg and P Negri (Coopération médicale belge); J P Collart (Bubanza Hospital); P Kabondo, A Kiromera, E Ndabanze (University of Burundi) and F Barin, virologist (University of Tours, France);
Table 1: Cryptococal meningitis (Bujumbura)¹

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<tbody>
<tr>
<td>Number of cases</td>
<td>–</td>
<td>–</td>
<td>2</td>
<td>8</td>
<td>24</td>
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Table 2: Incidence of esophageal Candida diagnosed by gastroscopy (Bujumbura)²

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<tbody>
<tr>
<td>N/gastroscopies</td>
<td>1/601</td>
<td>2/888</td>
<td>6/1630</td>
<td>17/1743</td>
<td>83/1567</td>
</tr>
<tr>
<td>%</td>
<td>0,1</td>
<td>0,2</td>
<td>0,4</td>
<td>1</td>
<td>6</td>
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Table 3: Kaposi’s sarcoma diagnosis confirmed by biopsy (Bujumbura)³

<table>
<thead>
<tr>
<th>Year</th>
<th>1974 – 1983</th>
<th>1985 (January – October)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>39</td>
<td>25</td>
</tr>
<tr>
<td>Number per annum</td>
<td>4.8</td>
<td>29</td>
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In 1984, Nathan Clumeck and his colleagues published a description of twenty-three cases of AIDS which had been observed in Belgian hospitals between 1979 and 1983⁴. Of the twenty-three patients, fourteen men and nine women, from the Republic of Congo (18), Rwanda (2), Burundi (2) and Chad (1), not one showed any of the risk factors described in American cases (homosexuality, intravenous drug taking, blood transfusions, stay in Haiti). This publication confirmed the existence of AIDS in central Africa and showed that the epidemiological characteristics could be very different from one region in the world to another: in central Africa, heterosexual transmission seems to play a major role.

**Evaluation of the gravity of the problem**

At the beginning of 1985, in order to assess the gravity of the problem at the national level, a team of Belgian, French and Burundian doctors proposed to the Burundian minister of health that they carry out a study on seroprevalence in urban milieus (Bujumbura) and in rural areas in the three natural regions of the country (plains – altitude 800 metres / central plateau – altitude 1500 metres/ Congo-Nile heights – altitude 2000 metres)⁵. For this project, the team benefited from the technical support of the virology laboratory at the University of Tours (Francis Barrin) which carried out the tests for the identification of the anti-HIV antibody (ELISA) and the Western Blot tests.

The investigation took place from March to July 1985. At risk subjects or those who were suspected of being at risk (soldiers, doctors, nurses) were excluded from the sample as were those who had a history of sexually transmitted diseases, blood transfusions or clinical signs compatible with an HIV infection: candidose buccale, polyadenopathies, tuberculosis. A

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² Ibid.
control test took blood samples from patients who came to Bujumbura for consultations for sexually transmitted diseases and from patients with tuberculosis.

**A survey with unexpected results**

In 1985 the epidemic was already having a serious effect on the capital. The average level of those who were HIV positive, regardless of age of sex, was 6,1% (22/362); it reached 10,2% in those older than fifteen (19/187). In the plains as on the heights, the overall rate was extremely low (0,4%). In the central plateau the level reached 3,7% but, importantly, most of the positive blood samples came from women who lived in an area near to the Tanzanian border which was a stop-over point for truck drivers. Everywhere there was evidence of those between the ages of naught and four being HIV positive (corresponding to mother-child transmission), the absence of infection between five and fourteen, an earlier age for infection (fifteen years and twenty years respectively) and a higher level of infection in women than in men (transmission though heterosexual relations). Amongst those who had tuberculosis prevalence reached 36,6% confirming the impression that, in Africa, there is a link between AIDS and tuberculosis. Amongst those who were treated for sexually transmitted diseases the rate was 29%. There was a reassuring note: the absence of infection in those who were between the ages of five and fourteen and who lived in the plains which is a region for endemic malaria would seem to argue against the hypothesis that mosquitoes play a role in the transmission of the virus.

**Table 4: HIV prevalence according to the geographic situation (regardless of age or sex)**

<table>
<thead>
<tr>
<th>Rural areas</th>
<th>Urban areas</th>
</tr>
</thead>
<tbody>
<tr>
<td>People tested</td>
<td>242</td>
</tr>
<tr>
<td>HIV + people</td>
<td>1</td>
</tr>
<tr>
<td>%</td>
<td>0.4</td>
</tr>
</tbody>
</table>

**Table 5: Prevalence of HIV amongst those older than fifteen**

<table>
<thead>
<tr>
<th>Rural areas (all areas)</th>
<th>Urban areas (Bujumbura)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of tests</td>
<td>457</td>
</tr>
<tr>
<td>Number of HIV-positive people</td>
<td>10</td>
</tr>
<tr>
<td>%</td>
<td>2.2</td>
</tr>
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</table>

In their innocence, the authors of this investigation believed that this initial collection of data from the entire country showed important results. It showed that in 1985 the urban milieu – Bujumbura - was more seriously affected than rural milieus; it offered reassurance to those who feared the possibility of transmission by mosquitoes; it confirmed the existence of “mother to child” transmission; it suggested that migrant labourers were “potential disseminators” and that there was an increased risk of contamination at stop-over points for truck drivers.

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For the future, these facts should facilitate the elaboration of a strategy for national prevention based on a policy of information, education and the promotion of the use of condoms.

To the utter astonishment of the clinicians, the Ministry of Health’s reaction was totally negative. It was accompanied with an avalanche of prohibitions, particularly that of presenting the results of the investigation at the first conference on “AIDS in Africa” (Brussels, December 1985), of taking the floor during the conference and of publishing the findings in a medical journal. The clinicians were accused of cheating because, according the Director General of Health, “[they] showed a preference for taking blood samples from at risk patients so as to exaggerate the extent of the problem”! In addition, the technical competence of the virology laboratory at the University of Tours was questioned.

Just as dismaying was the reaction of the Head of the Coopération médicale in Brussels: he showed no interest whatsoever! As for the difficulties that the Belgian doctors experienced with certain Burundian authorities, there was no end.

The attitude of denial by the Burundian authorities was doubtless the result of a fear of attracting “international” opprobrium regarding the morality and the sexual behaviour of the Burundian population. It was also because of a fear of seeing investors and tourists turn away. “It’s better to ignore the problem”. This political denial would last for three years and would retard the setting up of a programme of prohibition.

In 1989, a second investigation into national HIV prevalence, organised this time by the Ministry of Health, indicated that the average level in Bujumbura – regardless of age or sex – had risen from 6.1 to 11.2% and in the older than fifteen group from 10.2 to 19.5%.

The prohibition on publication in a medical journal resulted in the breakdown of links which had been established by our group and the Universities of Tours and Harvard. Interested in the results of the enquiry, they proposed the development of a research programme in Burundi.

Disgusted by the accusations of cheating, the pharmacist/biologist Éric Petat handed in his resignation. The final blow came at the beginning of 1987 when the Burundian Ministry of Health decided to interrupt brutally the investigations organised by the epidemiologist and statistician Baudouin Standaert. His office was broken into, his documents confiscated and he was asked to leave Burundi a few weeks later. Deprived of a biologist and a statistician, the Bujumbura team found itself permanently unable to function.

**HIV infection and racism**

The already strained and politicised atmosphere deteriorated even more with the publication of the existence of close genetic links between the simian virus (SIV) and HIV which suggested that the latter was a mutation of SIV. Commentaries of a racist nature were published in the media: not only were blacks attributed with unrestrained sexuality but some of them were depicted as indulging in sexual practices with animals which would have facilitated the transmission of the simian virus to humankind and would have provoked, after mutation, the unleashing of the AIDS epidemic. These disagreeable remarks angered Africans and the resultant tension was unpleasantly felt during the visit of the director of WHO-Africa to Bujumbura. During an interview he insisted on the fact that AIDS in Africa was an African problem and he discredited the work of the foreign researchers.

**The Catholic church’s erroneous message**

Homosexuality, drugs, sexual promiscuity, blacks with “unrestrained sexuality who indulged in bizarre practices”, all these characteristics were bundled together from the very beginning of the epidemic and gave rise, throughout the world, to an aggressive stigmatisation of people
infected with HIV, a stigmatisation which, in the United States, was extended to the carers of AIDS sufferers.¹

In Burundi, one of the poorest African countries, with a largely Catholic population, the researchers, faced with a sexually transmitted epidemic, waited for the church to condemn the stigmatisation and to be less strict concerning the use of condoms. Sadly, instead of showing compassion and comprehension, instead of seeing humankind in its daily reality with its weaknesses and its physiological limitations, the church’s message was God-fearing, moralising and accusatory, restricting itself to ideal and utopian propositions such as abstinence, chastity and absolute fidelity. In addition, it condemned the use of condoms either as a form of protection against a fatal disease or as a means of contraception.²

This stance denied the realities of life, particularly the economic ones, as much for men as for women. In fact, poverty often forced men to delay marriage or to move on their own towards the capital in search of work. The migrant worker who is separated from his family for prolonged periods often turns towards prostitutes, unaware of the risks and uninformed regarding protective measures. As for women, extreme poverty often forced them into prostitution which was frequently the only means of survival.

The church’s inappropriate message, which would always remain unchanged, was proclaimed during Pope John Paul II’s visit to Rwanda and Tanzania in September 1990. During this visit and on the occasion of an address to the diplomatic corps posted in Dar es-Salaam, the pope declared: “Even more harmful are the campaigns which expressly promote – by the absence of moral content and the false hopes which they engender – the forms of behaviour which have contributed to the development of the disease”.³ This message was repeated by Archbishop Javier Lozano Barragan, president of the Pontifical Council for Health Pastoral Care, during a meeting of theologians and doctors held at the Vatican in November 2000. “Condoms are not helping much because the disease is spreading”. In the final count, “chastity is the law of God” and “condoms are morally illicit” even for couples where only one has AIDS.⁴ At the meeting of the International Forum for Catholic Action held in Bujumbura in August 2002, Archbishop Simon Ntamwana, president of the Catholic bishops of Burundi, expressed himself in similar terms: “As far as the church is concerned, AIDS is and will remain a moral evil and the narcissism of condoms will not help at all. In fact, the condom has many uses which only confirm the egoistic and exclusive pleasure of the user.”⁵

**Dashed hopes**

In 1987 Professor Ziriwabagabo Lurhuma, head of the Department of Immunology at the Faculty of Medicine in Kinshasa announced that he had perfected a medication which was effective for the treatment of AIDS. This treatment, a true miracle, was well tolerated, easy to make and was particularly cheap: ten American dollars for a cure. Its name MM1 referred to Presidents Mobutu Sese Seko of Zaire and Mubarak of Egypt. What was it made of? No one knew but the reputation of the Zairian researcher and of Zaire under the direction of its guide,

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reached the peaks of glory. The news soon reached Bujumbura which teemed with desperate people. Some had money. Nobody knows how many made the journey to Kinshasa to obtain this MM1, but this so-called scientific progress, supported with much fanfare by the Zairian presidency, soon proved itself to be without foundation. It was the cold water poured onto high hopes.¹

Untimely meddling in AIDS research by a political power whose sole aim is to promote the country in the media is not specific to Africa. In October 1985 the French Ministry of Social Services triumphantly announced at a press conference that French doctors had found an effective treatment against AIDS: cyclosporine. However, the unfavourable deterioration of all the patients who were treated, rapidly contradicted these optimistic conclusions: this so-called success, imprudently announced to the media, was a failure.

In 1987 the first results of the treatment of AIDS with AZT were published; they were so encouraging that the research was prematurely interrupted for ethical reasons. In the following months, in Europe and in the United States, the enthusiasm unleashed by the AZT monotherapy would cool off because of the rapid development of the virus’ resistance to the medication. In Africa, the miracle of AZT which had caused so many to dream, was simply inaccessible because of its exorbitant cost. Another disappointment for those who did not want to die.

In 1990 Dr Davy Koech, director of the Kenya Medical Research Institute (KEMRI), announced the perfecting of “Kemron” an interferon alpha which was orally administered in small doses. According to him, in a group of 204 HIV-positive patients, 18 became HIV negative. After six weeks, the CD4² significantly increased and the general condition of the patients was much improved. Once again, the Burundians would make the pilgrimage, full of hope, but they too would be disappointed. No follow-up study would confirm the magnificent results observed by Dr Koech.³

Daily encounters with death

From 1985 doctors would gradually discover “exotic” diseases associated with AIDS – cryptococcosis, cerebral toxoplasmosis, pneumocystis carinii pneumonia, isospora belli intestinal infection. Given the lack of infrastructure for carrying out investigations and the Ministry of Health in Burundi’s very limited budget for purchasing medications, the clinicians often remained powerless and had to be satisfied with proposing diagnosis and observing. Thus cryptocal meningitis which is common and easy to diagnose is practically impossible to treat because six weeks’ of amphotercine B can cost 100 000 Burundian francs in a country where the average monthly salary is less than 10 000 francs. If the patient does survive his opportunistic infection, there is no adequate structure to ensure the continuity of the care required for his state of immunosuppression.

With the rapid increase in the number of patients who are hospitalised for AIDS and who are in a terminal state, each day brings its quota of deaths. These daily deaths which create a feeling of hopelessness, leave the nurses and doctors frustrated, discouraged and exhausted. The simultaneous infection of several members of the same family is another reason for the stress experienced by patients and medical staff: regularly father, mother and children are infected with repeated hospitalisations followed by a string of deaths. The

¹ Omololu Falobi, “Abalaka: Where the media went wrong”. <Nigeria.aids.org. April 1, 2000>. See also in the same volume César Nkuku Khonde’s contribution.

² The CD4 lymphocytes play a major role in the body’s immune response. They are among the main target of the HIV virus.

increase in the number of orphans is an enormous problem even for the extended African family which is traditionally ready to accept the children of brothers and sisters who have died. Finally, even the medical fraternity is being infected more and more by the disease.

In spite of this demoralising situation, neither from the Burundian government nor the Belgian volunteer services has organised a modicum of psychological support for the staff dealing with AIDS sufferers.

At the end of 1986, tired of seeing young patients passively awaiting death, the author of this article decided to institute a more positive undertaking in the hopes of improving the quality of and perhaps the hope for life. In order to achieve this aim, it was necessary to combine the prevention of certain opportunistic diseases, a period of clinical follow-up, continual information and education and basic psychological support founded on the establishment of a relationship of trust.

The prevention programme targeted tuberculosis, cerebral toxoplasmosis, non-typhoid salmonella sepsis, isospora belli intestinal infections. Often found in those who have AIDS, these infections are controllable if the patient regularly takes small doses of relatively cheap medicines (isoniazide for tuberculosis and trimethoprime-sulfamethoxazole for the others).

In 1987, in order to study the potential of ketoconazole as a primary prophylactic in cryptococcal meningitis, the pharmaceutical firm Janssens agreed to provide this medicine so that random clinical tests could be carried out. Unfortunately, the difficulties between Dr Standaert and the Ministry of Health occurred at the same time, interrupting the tests and causing another failure in the research domain for the Bujumbura team of clinicians.

With the passing years the epidemic has not ceased to spread, the number of sick people admitted each month for complications linked to immunosupression continues to rise. AIDS patients occupy more and more beds to the extent that one begins to wonder what happened to those suffering from other illnesses.

The families’ response

The stigmatisation attached to those suffering from AIDS in a world-wide scourge which has not spared Burundi. However, each day clinicians witness the admirable behaviour of relatives who accept to share precariously – or rather to survive in – sometimes for weeks on end, the same room as the ill person so as to bring some little comfort. In fact, most of the classical nursing (washing the patient, changing clothes, feeding, taking him/her to the toilet, making the bed) is undertaken by family members so that the nursing staff, always too few, can get on with more medical activities (taking blood samples, inserting drips, monitoring changes, noting clinical history…).

End of the Burundian experience

In October 1993, another drama exploded: civil war. According to estimates, it was responsible for approximately 200 000 deaths in a matter of weeks! Even AIDS was relegated to second place. In July 1994 all development projects were halted. With no possibility of a short or medium term political solution, the vast majority of volunteers left Burundi.


The AIDS epidemic is rife in KwaZulu-Natal: less than 2% in 1990, the level of HIV prevalence in prenatal clinics reached 19.9% in 1996. These figures have no more than an illustrative value as they include only Black and Coloured (mixed race) women of child
bearing age who attend governmental pre-natal clinics. There are no statistical data for other women and for men. Random blood samples taken since 1990 in pre-natal clinics in all the other provinces show that the distribution of the infection is not homogeneous: in 1996 the Western Cape Province was hardly affected (3.09%), whilst the provinces of KwaZulu-Natal (19.9%) and North-Western Province (25.13%) were seriously affected.

**Why this explosion?**

The racist political regimes which have succeeded one another since the 19th century as well as the economic changes affecting the country have created ideal conditions for the spread of AIDS which is a sexually transmitted disease. After the discovery of diamonds in 1867 and of gold in 1886 the economy was founded on the exploitation of an abundant work force which was under paid and which had no rights. Cut off from their families for long periods the workers were confined to camps with the most basic of sanitary installations and with no medical care. In 1985, 1 833 636 South Africans were migrants to which could be added hundreds of thousands of workers from neighbouring African countries (Mozambique, Botswana, Lesotho) or from countries further a-field (Angola, Malawi). Unfortunately migrant labour did not vanish with the end of the apartheid regime and this contributed to a large degree to the AIDS explosion during the 1990s1.

Other factors would play an exacerbating role. One of these is the lack of information available to the Black community. The AIDS Unit created by the de Klerk government in 1990 was charged with diffusing information on sexually transmitted diseases and AIDS amongst the population. After two years of work, this unit was disbanded, the prevention programme interrupted, financing cut off and information in the media limited to the English and Afrikaans languages.2 In 1996, two years after the end of apartheid, this linguistic gap remained evident: most of the information posters on AIDS, sexually transmitted diseases and tuberculosis which adorned the walls of the largest hospital in Pietermaritzburg were written in English whereas only a minority of the patients understood this language.

The stigmatisation experienced by HIV victims from the population in general and from the health sector in particular contributes to the spread of the epidemic. This stigmatisation can be seen on a daily basis amongst nurses and doctors whether they are white, black or Asian. Afraid of being recognised as HIV positive, the patients adopt an attitude of denial which makes the clinicians’ work difficult and which hampers the effectiveness of prevention programmes.

According to an investigation in a medical faculty in Johannesburg (doctors, physiotherapists, nurses, dentists, pharmacists) at the end of the 1990s, 36% of the students felt that they had the right to refuse to treat AIDS patients and 24% believed that they could retain this right after having received their diploma or degree. Furthermore, many students admitted to having witnessed discriminatory behaviour on the part of those who were supposed to be setting an example.

In 1998 a young black woman from the Durban region, a voluntary worker for a national organisation for those living with AIDS was stoned to death by her neighbours for having admitted that she was HIV positive during the ceremonies on World AIDS day on the 1st December 19983.

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KwaZulu-Natal

Poverty, unemployment, dislocation of families, separation of couples for economic reasons, loss of cultural identity, low level of education, physical and sexual violence, all contributed to the spread of AIDS in the country. However, it is unclear as to why the distribution of HIV prevalence is not homogeneous or why KwaZulu-Natal figures amongst the provinces the most affected since the beginning of the epidemic (Table 7) given that there are few mines and few migrant workers. Political disturbances which continued in this province after 1994, the presence of the port of Durban, the largest in Africa, the heavy road traffic between this city and the interior of the country have all doubtless played an important role in the spread of the epidemic.

Table 7. Level of HIV amongst women attending prenatal clinics

<table>
<thead>
<tr>
<th>Year</th>
<th>Western Cape</th>
<th>Eastern Cape</th>
<th>Northern Cape</th>
<th>Free State</th>
<th>KwaZulu Natal</th>
<th>Mpumalanga</th>
<th>North West</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996</td>
<td>3.09</td>
<td>8.10</td>
<td>6.47</td>
<td>17.49</td>
<td>19.90</td>
<td>15.77</td>
<td>7.96</td>
</tr>
<tr>
<td>1998</td>
<td>5.20</td>
<td>15.90</td>
<td>9.90</td>
<td>22.80</td>
<td>32.50</td>
<td>30.02</td>
<td>11.50</td>
</tr>
</tbody>
</table>

A factor which could facilitate the spread of AIDS is the practice of *dry sex*. Unknown to the majority of doctors, never spoken about, in other words, denied by the population, *dry sex* is difficult to evaluate. An investigation carried out by Neetha Morar for the Medical Research Council of KwaZulu-Natal amongst women and prostitutes showed that many men insist that their partners practice *dry sex*. This consists of totally drying all vaginal mucus before sexual relations take place. This drying, using different means, causes physical damage to both the women and the men thereby increasing the risk of the transmission of AIDS.

*Dry sex* is not unique to South Africa or to KwaZulu-Natal but seems to be particularly popular in this province. Despite almost daily conversations with Zulu counselors in HIV clinics in Pietermaritzburg, the author would never have heard of the existence of *dry sex* had he not have discovered, quite by accident, Neetha Morar’s article in *The Lancet*. Even if they still have to be proved, her conclusions need to be taken seriously and it would be prudent to inform those who practice this form of sex.

Taking charge of AIDS in Pietermaritzburg hospitals

With a level of HIV exceeding 30% it is not surprising that doctors’ waiting rooms are packed with patients who have complications suggestive of a state of immuno-suppression. The exact number of AIDS patients who are hospitalised is unknown because many refuse to submit to an HIV test. As medical files are vague about the diagnoses of AIDS, hospital statistics have little value. If a visitor were to have the ludicrous idea of asking for facts and figures he would be given the answer: “There are a lot … at least 50% of medical beds”.

Feelings of powerlessness, of frustration, of waste of energy and money reign supreme amongst health workers, national and foreign. Communication with the families of the ill is almost non-existent. Listening to them, one would think that the patient is suffering from pneumonia, tuberculosis or diarrhoea but certainly not AIDS. Whilst one in three adult members of the Black community is infected with HIV, AIDS does not exist for the greater majority.

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1 Statistics provided by the Department of Health.
In 1997, the Department of Medicine in the two public hospitals in Pietermaritzburg – Greys Hospital and Edendale Hospital – agreed to open, in each hospital, a clinic to deal with those who are HIV positive. So as to hide their link with AIDS, these clinics were called “Communicable Diseases Clinics” or CDC. Their aim was to curb the decrease of CD4, to improve the quality of life, to keep the patients economically active for as long as possible, to increase their life expectancy hopes in spite of the impossibility of access to antiretrovirals whose cost is exorbitant.

The general approach suggested is similar to that which was developed in Burundi. It aims at reducing the impact of opportunistic infections on the viral charge and the immune system by combining prophylaxis and treatment of active infections. It also aims at improving nutrition and reducing psychological stress which is so frequently found amongst those who are infected with HIV.

Since the outbreak of the epidemic, the usefulness of a prophylactic programme has been confirmed by different studies carried out in Haiti,1 Ivory Coast,2 United States.3 In this latter country, the survival percentage twenty four months after an opportunistic infection signaling the AIDS status was only 10-20% during the 1984-1991 period. This rate increased significantly between 1992 and 1995 and reached 20-35% with the implementation of a prophylactic programme. Since 1996 the use of tritherapies has had an even more spectacular impact: 80% survival two years after an opportunistic infection.4

Patients’ opinion of the two clinics has been favourable as is proved by the growing number of new intakes and the long distances – from 100 to 500 kilometres – that some have to travel in order to be treated. An audit undertaken by the University of Natal in 2001 confirmed this impression. The absence of stigmatisation and the possibility of asking questions affecting all aspects of infection problems are particularly appreciated.

Even though the progress of the epidemic becomes more evident and more worrying every day, the management of the two hospitals show little interest in the problem. In six years they have not once visited the clinics and, until recently, have had no idea of what the treatment consists. This lack of interest is particularly noticeable at Edendale hospital: the information board at the entrance of the main building indicates everything, including the kitchen and the morgue, but not the clinic for infectious diseases. At Greys hospital, new management and the announcement of the upcoming governmental programme for antiretroviral treatment have considerably improved the situation.

**Waiting for an life line**

Whilst the two clinics are appreciated by those who are ill, they nevertheless have important inadequacies. They can admit only a very limited number of patients, far below the demand. For the sick who come from rural areas, the financial cost of regular visits to the hospital – travel and consultation – is too onerous and is the main reason for drop-out – 30% of the patients. There is a crying need for outlying structures to which those who do not show major clinical problems could be referred. It is for this reason that, in 1999, the author suggested to the Department of Health in KwaZulu-Natal that a system which could help more rural patients be set up, a system which would integrate all levels of care and one which would include members of the rural community. They would play a major role: distribution of

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medications, ensuring that treatment was adhered to, early detection of alarming clinical signs followed by appropriate referral to higher levels of caring. The proposition was accepted by the Department of Health but could not be implemented because of a lack of funds.

In January 2002, members of the Enhancing Care Initiative project (ECI) which associates the universities of Natal and Harvard were informed of the impending launch of Global Funds for the fight against AIDS, tuberculosis and malaria, an organisation founded by the United Nations. In March 2002 the KwaZulu-Natal sites involved in the ECI project presented seventeen requests for financing. All were accepted with the promise of budget of 72 million American dollars spread over a period of five years!

After several days of joy not to mention euphoria, a period of frustration and conflict, which was to last for an entire year, began. The national Department of Health delayed signing the agreement on the pretext that the promoters of the ECI project had gone directly to the Global Fund without respecting the hierarchical route. In August 2003, the problems appeared to have been ironed out and new documents were urgently prepared. On the 1 February 2004 the first funding became available.

**The battle for antiretrovirals**

From 1996, date of the first tritherapies, to 2000 when the International AIDS Conference was held in Durban, the hope of seeing antiretrovirals forming part of the treatment for African patients was a utopian dream: the cost of the medications and of biological tests (CD4 and viral charge) is exorbitant whilst the logistical problems appear insurmountable. On the other hand, public hospitals already guarantee prophylactic treatment (AZT+3TC) for paramedics who have come into contact with contaminated material.

After the Durban Conference, the cost of medication gradually and considerably diminished but still not enough to make it accessible to the majority of patients. Growing pressure was being put on the government by NGOs like Treatment Action Campaign (TAC) a remarkable pressure group lead by Zachie Achmat. Their aim is to get central government to develop, a rapidly as possible, programmes for “mother to child” transmission, prophylactic treatment of rape victims and, finally, programmes for the sick in public hospitals.

At the end of 1999, President Mbeki, for reasons which are still difficult to understand, threw his lot in with the “dissident” theory on AIDS which rejects the role of a virus in the development of immunodepression and attributes the disease to the evils which ravage most of Africa: poverty, malnutrition and tuberculosis. As the role of the virus is questioned, there is no reason to develop treatment programmes aimed at HIV. The usefulness of antiretrovirals is denied or denigrated whilst their toxicity is constantly brought to the fore.

Pressure groups nevertheless gained important victories: a national programme for the prevention of mother to child transmissions was finally accepted and set up in 2001; rape victims have been provided with prophylactic treatment since 2003.

Since 2001, the gradual drop in price has allowed a growing number of the sick who frequent HIV clinics in Pietermaritzburg to purchase antiretrovirals. This “favoured” group, very much in the minority (10%) provides us with the opportunity of gaining a certain amount of experience, of assessing the effectiveness of the treatment even where there is extreme immunodepression and to deal with the sometimes very serious secondary effects particularly in the least expensive way (ddi + d4T). The often very favourable progress made by those who are treated compared with the inescapable deterioration of the others is cause for anxiety amongst the medical staff.

In August 2003, the South African government announced that it would be prepared to supply free antiretrovirals to patients who are severely immunodepressed (CD4 inferior to 200/ml) and to ensure the clinical and biological surveillance (CD4 and viral charge). Each
province has to draw up a plan of action and identify the needs with regard to staff, equipment and premises. The ARV Roll-Out Programme (distribution of antiretrovirals on a massive scale) will begin in March 2004.

If the availability of antiretrovirals is a relief for daily clinical activity there is no doubt that the associated problems will be enormous and difficult to manage especially when it is a question of reaching the rural population on a large scale: several hundred thousand HIV-positive people are already potential candidates and this number will grow daily. Thrilling but worrying.

Conclusion

Twenty years have gone by since the identification of the first cases of AIDS in Africa. A mass of clinical, biological, sociological and economic information has been collected. For those who live in daily contact with the sick, these years have brought an enormous amount of satisfaction on both the human and intellectual level. But they have also caused frustration, annoyance and anger.

In developed countries, and more and more in South Africa, the caring of patients has changed and long term prognosis has improved. However, the medication which is at present available is not the solution to controlling this epidemic because it does not kill the virus and it necessitates a life-long treatment. It is to be hoped that more effective medicines will become available in the not too distant future. Even more important is the perfecting of a vaccine that will be tolerated, easy to administer effective, ensure long term protection and be accessible to all.

In the mean time, all forms of the fight against the epidemic, whether they be clinical or preventative, need to be loudly and strongly supported by political, moral and religious leaders.

(translated from the French by Carole Beckett)
Historical Trends in the HIV/AIDS Training of Health Care Workers in the Western Cape, South Africa, 1990-2003

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Introduction

South Africa has one of the largest and most rapidly expanding HIV/AIDS epidemics in the world. Health care workers play a crucial role in the prevention and treatment of HIV/AIDS, and their training is vital to the management of the epidemic. Training organisations have, over time, become a central component of any HIV/AIDS strategy. They are at the forefront of much of the innovative action research in the field, yet not much of this experience is documented. Thus, training organisations are significant new sources of information, opening up fresh historiographical questions. It is useful both to understand the shifting trends in training content and methodology, and to examine the underlying historical factors contributing to these shifts. This study examines this fissure in the current literature.

This paper begins with a literature review and an overview of how the historical analysis was conducted. The key findings are then presented in terms of the shifts observed in training content and methodology. These shifts are then analysed according to the primary contributing historical factors.

Literature Review

The output of biomedical HIV/AIDS research is considerable and well established. There is a noticeable lack of social scientific research, particularly in Africa. As early as 1991, in Africa, it was noted that HIV/AIDS policies and programmes should reflect a balanced biomedical and social effort. In 1998, it was argued that HIV/AIDS is not simply a health problem and that the underlying economic, social, and political factors of the epidemic need

2 In this study, health care workers refers to professional and student doctors, nurses, psychologists, social workers, and counsellors involved in HIV/AIDS prevention, treatment, support, and care. Trainers and staff in HIV/AIDS non-profit, community, and faith-based organisations are also included. Finally, because of their central role in providing HIV/AIDS prevention, care, and support, home-base carers, community health workers, traditional healers and peer HIV/AIDS counsellors and educators were also included. There have been calls to broaden the definition of HIV/AIDS health care workers, in order to make it more inclusive of all the various people involved with HIV/AIDS treatment and care. See, for example, WHO, ‘The World Health Report’, (2004). <http://www.who.int/who/2004/en/> (Accessed: 10 January 2005).
4 Ibid., 5.
5 See Philippe Denis’ introductory chapter.
to be addressed.\(^1\) Barnett and Whiteside (2002) explored the role of HIV/AIDS in the context of globalisation and development.\(^2\) The complexities of HIV transmission and the failure of interventions have been traced to local economies, increasing poverty, migration, gender, war, and cultural politics.\(^3\)

Since the mid-1990s, there has been increasing historical research and involvement in the field. Examples of historical HIV/AIDS research in Africa include investigations of migrancy,\(^4\) labour,\(^5\) sexual relations and transmission,\(^6\) sex workers,\(^7\) manhood,\(^8\) attitudes and behaviour,\(^9\) and historiography.\(^10\) Important contributions to the history of the epidemic come from researchers like Grmek,\(^11\) Hooper,\(^12\) and biomedical scientists like Korber,\(^13\) Bailes,\(^14\) and Gao.\(^15\) In 2006, Iliffe made an important contribution to the history of HIV/AIDS in Africa.\(^16\) In South Africa, there have been historical contributions by Grundlingh, Fassin, Schneider, Denis, and Phillips.

Examples of greater involvement from historians include, first, the “AIDS in Context: Explaining the Social, Cultural and Historical Roots of the Epidemic in Southern Africa” conference (Johannesburg, 4 - 7 April 2001).\(^17\) The goal of this conference was to examine the specific interaction of historical, social, political and cultural factors that have formed the nature of the HIV/AIDS epidemic. Second, the \textit{African Journal of AIDS Research (AJAR)}\(^18\) was launched in 2002. The AJAR’s goal is to contribute to the understanding of the social

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dimensions of HIV/AIDS in the African context. The contributions to this journal are interdisciplinary, including contributions in the field of history.

While there are a growing number of international HIV/AIDS training guidelines, there are noticeably few historical analyses of training. When training has been addressed, it has been part of historical analyses of HIV/AIDS issues like education, awareness, and counselling. Training organisations find it difficult to provide an historical critique of what training has worked and why it has worked. These organisations often need to respond to external demands from clients and health care services without having the necessary time to evaluate and reflect on best practices. This has resulted in ahistorical and decontextualised planning and assessment of training programs. This study examines the relevant historical factors in training organisations.

Method
An historical analysis of key HIV/AIDS training organisations in the Western Cape, South Africa was conducted, covering the period 1989-2003. The organisations studied specialise in the HIV/AIDS training of health care workers and peer counsellors. While the goals of the training organisations vary, they all prepare health care workers to work in HIV/AIDS prevention, care, and support. The trainees are drawn from the provincial health care department, as well as non-profit, faith-based, community-based, university, and corporate organisations. The acquired training skills are utilised, essentially, with patients in the primary health care system.

Information was gathered from HIV/AIDS training organisations by analysing training material, interviewing training managers, trainers, counsellors, and supervisors, collecting feedback from course participants, conducting site visits, analysing ongoing evaluation of programs, and analysing personal experience as a trainer for various organisations. This information was then analysed for significant historical trends in training content and methodology.

Results
The analysis showed that there have been major shifts in both training content and methodology over the last 14 years. Placed on a timeline, the shifts accord with four periods:

1 For example, see organisations like UNAIDS, CDC, International Training and Education Center on HIV, Center for AIDS Research, WHO, World Bank, The Synergy Project, IntraHealth International.


5 These organisations are: Aids Training, Information, and Counselling Centre (ATICC) (it has trained the majority of health care workers in the province); Lifeline/Childline HIV/AIDS Program; Department of Health – Western Cape; Somerset Hospital – HIV/AIDS Unit; Red Cross Society; Student Health Services (University of Cape Town); Final Year Medical Student HIV/AIDS Training, Department of Medicine (University of Cape Town); Department of Psychology (University of Cape Town); Philipi Trust HIV/AIDS Training; FAMSA; Helderberg HIV/AIDS Program; Leadership South HIV/AIDS Program; Irving & Johnstone Pty.; and the Rape Crisis Centre.
Facing the Challenge of HIV/AIDS

Once these basic shifts were established, the predominant themes of each time period were then analysed. The themes were organised into shifts in content and methodology. A brief description of these shifts is provided before discussing the contributing factors.

**Shifts in contents**

First, in terms of the shifts in content, each period was characterised by the following:

(1) **1990-1994**

In this initial period organisations provided basic HIV/AIDS information, awareness, and skills. Also, these organisations found themselves in an advocacy role, highlighting the importance of the growing epidemic and the subsequent human rights issues. Training during this period was difficult and often frustrating because of government, public, and professional disbelief and inaction. Many trainees felt that they were forced by their managers to attend training courses.

(2) **1995-1998**

The number of reported HIV-positive persons began to increase significantly. This was largely due to the fact that the government had implemented the primary health care model, and patients who were previously limited to a few specialist clinics now attended community clinics. Training was now in demand, and organisations began to focus on high incidence prevention, treatment, and care input. Trainees reported that they felt overwhelmed by the increasing number of patients and the lack of resources within the healthcare system. This period was experienced as a time of accelerated skill acquisition and crisis management.

(3) **1998 onwards**

The infamous “Does HIV Cause AIDS” debate that was resurrected by President Thabo Mbeki and his advisors not only had an interesting effect on the belief structures of the South African and the international health community, but also on training organisations. Training managers and directors of NGOs stated that content was compromised during this period in that there was regression to many of the training issues of earlier years. Trainers had to return to the dissemination of the basic HIV/AIDS information of the early 1990s. Many health care workers had to be once again convinced of the scale and impact of the epidemic. Training organisations played an important advocacy role during this period in that they continued to provide facts and treatment options while the epidemic grew amidst confused public health messages.

(4) **1999-2003**

Trainees reported that they once again began to feel overwhelmed by the numbers of HIV-positive persons attending clinics and hospitals, and the increasing demands being made on health care workers and the health system. The last phase is characterised by program and
intervention specific HIV/AIDS input. It was now rare to encounter participants who did not believe in HIV/AIDS and its massive impact on their community and the country at large. Many participants received specialised and advanced training in the areas of treatment and counselling. Health care workers reported more agency in the prevention and management of the disease.

**Shifts in methodology**

Second, in terms of shifts in *methodology*, a more predictable observation was made. Over the 14 years it was shown that there was a shift from traditional teaching methodology to more adult-based learning methodology. With this shift came the move towards methodology that was more culture-, gender-, and language-sensitive. There were particular issues that were the focus of each period:

**(1) 1990-1994**

During this period training methodology was largely a continuation of the traditional and didactic training methods that were evident in previous regional training of health care workers. It was held that there was specific information to give, and it was given in the traditional classroom manner of trainers teaching concepts, and trainees taking notes.

**(2) 1995-1998**

The increase in the reported number of HIV-positive persons attending clinics resulted in more local examples. The traditional training methods were proving cumbersome and unsuccessful because trainees now had more experience and were more vocal about this experience. Thus, trainees were given the opportunity to share more of their increasing experiences and skills. Training organisations began to describe their work as facilitation rather than teaching or training.

**(3) 1998 onwards**

Despite the advances in methodology that the previous period witnessed, this period saw a split in methodology. For those trainees who became confused by the government’s reluctance to state that HIV caused AIDS, a return to more traditional methodology was witnessed. For those trainees who continued to work with high numbers of HIV-positive persons, there were continued advances towards more adult-based learning. Trainers complained that it was difficult facilitating courses when both positions were being expressed within the same group. This resulted in trainers having to work in two methodologies simultaneously when providing input on one topic.

**(4) 1999-2003**

This last period was characterised by a return to the principles of adult-based learning. The demand for innovative responses in a resource-limited environment led to more problem-, experience-, and peer-based learning. There was also a focus on training in rural areas and the utilisation of local skill bases in the provision of training. This led to the successful implementation of community-based train-the-trainer programs and capacity development
initiatives. This was a period of challenging new training demands and innovative methodological solutions.

Discussion

Once the main shifts in content and methodology and the four periods had been established, the contributing historical factors were grouped. Some of these factors can be generalised across the four time periods, while others are time- or event-specific.

Epidemiology

In South Africa, the collection of HIV/AIDS statistics is controversial. Since 1991, the annual National HIV Survey of Women Attending Antenatal Clinics has provided data in terms of national, provincial, and age group percentages. These figures have been questioned by various international and local sources. For example, in 2002, the Nelson Mandela Foundation/HSRC Study on HIV/AIDS argued that the antenatal survey is not nationally representative of HIV prevalence. In 2003, WHO/UNAIDS claimed that the antenatal surveys represent a significant underestimation. The government attacked the former study with its higher prevalence rates as being alarmist, and commended the second study because it gave cause for hope with its lower figures.

This diversity of opinion created confusion for the South African public, and it made it difficult for training organisations to present accurate national and regional statistics. Most organisations chose to present the results from the antenatal survey, despite its flaws, because this data was continuous from 1991 onwards. Even though statistics are regularly updated in training courses, many health care workers continued to question their validity and reliability based on their own lack of, or very close, association with HIV/AIDS. The former experience resulted in an underestimation, while the latter experience resulted in an overestimation of HIV prevalence. The resulting views had a profound influence on whether or not the presented statistics were seen as accurate, and how trainees responded to the rest of the training. It was common for trainers to present examples of trainees who have argued about the statistics, typically presented at the beginning of a course, and then to either leave the training or ignore further training input.

One training organisation reported that it was more useful to present the statistics in a low-key manner and rely on participants’ personal and work experience to discuss incidence and changing trends in the epidemic. In this way, the official statistics simply backed up or challenged experience. The same organisation claimed that in the last few years it was more useful to use the UNAIDS/WHO Classification of Epidemic States when dealing with statistics. This classification system uses three states to describe an epidemic, i.e. low, concentrated and generalised. Low refers to an HIV infection that has not spread to a significant degree in any sub-population despite its presence over a period of time.

4 Trainers, ATICC, Focus Group, April 2003, Cape Town.
5 Trainers, ATICC, Focus Group, April 2003, Cape Town.
Concentrated refers to an HIV infection that has spread rapidly and widely in a particular sub-population but is not established in the general population. Generalised refers to the state when HIV is firmly established in the population as a whole.

Participants responded more positively to the concept of classifiable states rather than fixed numbers. Presenting statistics continued to be problematic in terms of reliability, validity, availability, and government support thereof. This was especially true when working with participants from low-incidence areas. However, most health care workers today are working in high-incidence areas and the reality of AIDS in their daily work is enough to convince them of the enormity of the epidemic.

**Social factors**

Linked to the issue of statistics are the issues of social and occupational contact of health care professionals with HIV-positive persons. In the early 1990s, very few health care workers had worked with, or knew anyone personally, who was HIV-positive. By the mid-1990s, most health care workers had worked with HIV-positive persons and some had personal experience with an HIV-positive family member or friend. By 2000, all health care workers had been contact with HIV-positive persons professionally, and many more had personal experience. This shift in focus had important implications for the quality of course participation and attitudes towards HIV-positive persons.

Organisations argued that the principle here is simple and predictable: Greater personal or professional contact with HIV-positive persons results in more constructive involvement in training courses. All organisations claimed that social factors were more important than trainees’ education in assessing the quality of course participation; in fact higher education often served as a hindrance to constructive participation. For example, this was found when training nurses and doctors with fixed ways of approaching disease prevention and treatment.

Social exposure to HIV-positive persons became important in the choice of content and methodology. Up to 1995, trainers experienced many difficult course participants who had not been exposed to HIV-positive persons and would bring very unhelpful, moralistic views into the training room. For example, participants claiming that HIV-positive persons should be isolated like in Cuba; HIV-positive persons were being punished by God because of their promiscuity (a very popular word in training courses in the early days); HIV-positive persons do not deserve treatment; HIV is not a threat to anyone in a relationship or marriage. By 1995, exposure tempered some of these attitudes. By 2000, the complexities of issues like poverty, migrant labour, post-apartheid family structures, unemployment, and the sexual patterns between older men and younger women were well established, and, to a large extent, accepted.

While the growing epidemic, time, and exposure helped organisations deal with this issue, trainers also found that changing the training methodology helped to expose participants to the complex realities of HIV/AIDS. Some of their initiatives included: (i) bringing in HIV-positive persons from similar backgrounds to talk to course participants, (ii) identifying mothers, fathers, siblings, spouses who felt comfortable talking about the loss of an HIV-positive person, (iii) requiring participants to have some professional HIV/AIDS experience as a training entry requirement, and (iv) including practical training, under professional supervision, with HIV-positive persons as part of the course.

A final point highlights the impact of high incidence areas on the visibility and exposure to HIV-positive persons. Even though it is well known that HIV/AIDS is not

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1 Trainers, ATICC, Focus Group, April 2003, Cape Town.
limited to any economic group, it did accelerate in certain high incidence areas in the Western Cape. By the end of the 1990s, areas like Khayelitsha, Guguletu, Mitchell’s Plein, Nyanga, and Helderberg had been identified as high incidence areas. The reasons for the acceleration in these areas are linked to economic and social factors like unemployment and migrancy. Health care workers living and working in these areas brought relevant experience to training courses, and have often remained ahead of participants from low-incidence with lower social and professional exposure.

A pertinent related issue, especially before 1995, was the fear, and increasing number of reports, of occupational exposure to HIV. It was a topic that was often raised by concerned health care workers, and some training organisations assisted in establishing and communicating guidelines for HIV post-exposure prophylaxis and the management of potentially exposed health care workers. This issue continued to raise apprehension, but by the end of the 1990s health care workers were no longer as concerned because of the establishment of acceptable occupational prevention, exposure, and management guidelines.

**Political factors**

The impact of government response on knowledge, attitudes, and prevention strategies is profound. Centralist leadership is key to mobilising state organisations, foreign aid, and significant non-state involvement. South Africa has many examples from the last decade that illustrate the role of political figures and policy in aiding or confusing public understanding. The National Party government was slow to respond to HIV/AIDS. In 1994, the democratic government inherited a rapidly worsening epidemic. The ANC government immediately acknowledged the problem but, for various reasons, was slow to address HIV/AIDS in any significant way. Various government scandals ensued, which have continued to the present.

Training organisations reported that participants in the first few years of training claimed that the government’s lack of HIV/AIDS coverage confirmed certain trainees’ perception that the problem was not important enough for consideration. The growing epidemic and the number of HIV-positive persons reporting at clinics started shifting these perceptions. In 1999, when President Mbeki invited the dissidents to debate the HIV-AIDS link in South Africa, many people became confused after having begun to accept the realities of HIV/AIDS. There were numerous training examples of direct challenges from participants in response to accepted and well-utilised material. Many participants no longer believed the trainers. This was particularly evident in the training of content such as virology, epidemiology, statistics, and treatment strategies. There were also many reports from health care workers who stated that patients were openly declaring that they were no longer going to use condoms because even in the unlikely event of contracting HIV, they would not develop

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3 For example, (1) In 1995, there was Sarafina II, the AIDS musical and the accusations of financial mismanagement, (2) In 1997, then-deputy president Mbeki, and Dr Zuma (then-Health Minister), enthusiastically endorsed the toxic drug Virodene. There was a call from government to abolish the Medicines Control Council because it had criticised the government’s role and management of this issue, (3) The government’s alliance with the dissident view that “HIV Does Not Cause Aids,” (4) In 1999, Mbeki claimed that providing AZT was irresponsible because of its alleged toxicity, (5) In 2001, Mbeki used 1995 statistics to argue for lower prevalence rates in the country, and (6) In 2003, Mbeki denied that he knows anyone affected by the disease.
AIDS. Health care workers and NGOs claimed that the President’s stance had a long-lasting negative impact on clinic attendance, treatment, and the safer sex campaign.

An interesting example that illustrates the power of positive government messages comes from HIV/AIDS counsellors in Khayelitsha. Since 1994, a group of HIV counsellors walked home from the day clinic along a certain route that brought them into contact with the same group of teenagers. Often they would stop to talk to the teenagers, which was a good opportunity for sex education. The teenagers invariably told them that there was no such thing as AIDS, and hence they did not have to practise safer sex. Over the years the banter continued, and there was no change in what the teenagers believed. Then, in October 1998, then-deputy president Mbeki’s delivered the government’s HIV Address to the Nation. Then-president Nelson Mandela was scheduled to give this address and at the last moment this was changed and Mbeki delivered the address on behalf of President Mandela. The message of this address was: “The danger is real … [and] we can only win against HIV/AIDS if we join hands to save the nation.” A few days after the address the counsellors were walking home and were stopped by the visibly agitated teenagers. They said, “You were right, Ma, Aids does exist – Thabo Mbeki said so!”

This is not to imply that President Mbeki is solely responsible for the deleterious effects reported; as any historian knows, individual actions are the result of complex historical factors. The factors behind President Mbeki’s actions are interesting and multifarious, but beyond the scope of this paper. The overwhelming nature of the disease, the fact that it is predominantly sexual in transmission, and the inconsistent public health messages, resulted in a confusion that required strong HIV/AIDS leadership; something with which South Africa is still grappling.

**Cultural factors**

One of the major challenges facing training organisations is the incorporation of relevant cultural factors into their content and methodology. During the initial phase of the epidemic, it was common to hear trainees echoing what the larger community was saying, that is, HIV/AIDS, if it does exist, exists only in other cultural or religious groups. This is the familiar “Not Us-Them” response. There were also many conspiratorial, amusing, and alarming HIV/AIDS genesis theories that were related to this response. For example, “It is a white, apartheid disease,” “It is a black freedom fighter disease,” “It is an American disease brought in oranges,” and “P.W. Botha (the second-to-last apartheid leader of South Africa) manufactured this in a laboratory because he was forced out of political power.” Another paper awaits a detailed historical analysis of these HIV/AIDS genesis theories in Southern Africa over the last twenty years.

Dealing with these attitudes in training courses proved difficult given the power of conviction with which some trainees supported these views. Certain views were harmless, but others endangered public health. The most striking example comes from a traditional sexual practise, “dry sex.” This refers to the practice where men insist that their female sexual partners “dry” their vaginas before having sexual intercourse.

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1 Leadership South HIV/AIDS Counsellors, private communication, December 1999, Cape Town.
Facing the Challenge of HIV/AIDS

herbal remedies.¹ This is done for three main reasons: (i) certain men enjoy “tight” sex which means sex where there is more friction, despite the obvious discomfort to the woman, (ii) based on some traditional associations of vaginal fluid with being “unclean,” and a barrier to fertility,² certain men want dry sex in order to ensure “cleanliness,” and (iii) certain men believe that if a woman is “wet” it means that she has just had sex with another man and is thus being unfaithful.

While health care workers in Southern Africa were aware of this practice, they were not aware of its long history, prevalence,³ and role in HIV transmission.⁴ Researchers warned that dry sex could promote HIV-1 in that dry sex promoted lesions by damaging vaginal mucosa. Women who practise dry sex have been found to have vaginal inflammation resembling a chemical burn or allergic reaction.⁵ Moreover, it was unlikely that men who were insisting on dry sex would use a condom,⁶ a fact that had important implications for the condom distribution and safer sex campaigns.

Trainers reported that the topic of dry sex initially met with a stony silence from participants, particularly black women. After many unsuccessful attempts to discuss this, trainers decided to change their methodology. Rather than simply provide information, they attempted more group discussion without feedback, identifying older black women who were willing to discuss the issue, utilising the skills of older black women and men who were prepared to speak out against the practise, and using focus groups to gain access to the issue. These attempts proved successful in that participants started opening up about the issue. This led to more detailed and interesting discussions, which allowed participants to develop their own ideas and strategies about dealing with dry sex in day hospitals and clinics.⁷ Many older female and a few male health care workers included a discussion of dry sex in their pre- and post-test HIV/AIDS, and STI (sexually transmitted infections) counselling and education. Numerous examples of successful education and behaviour change interventions were reported in both female and male patients.⁸

This issue is by no means over, and Southern Africa needs to deal with the wider economic, gender, power, and legal issues in order to change this practice, and significant related issues like gender-based violence. It is important to note that some training organisations have been proactive and innovative in beginning to help health care workers understand and manage these problems.

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⁶ D. Civic and D. Wilson, ‘Dry Sex in Zimbabwe and Implications for Condom Use’, Social Science and Medicine, 42/1 (1996), 91-98.
Teaching ethics

Teaching ethics was one of the most complex and challenging tasks for HIV/AIDS training organisations.\(^1\) HIV/AIDS raises unique ethical deliberations, which encompass the four principles of medical ethics, patient autonomy, beneficence, non-maleficence, and social justice.\(^2\) Organisations begun dealing with these issues in 1989 and by the end of 2003 some of these issues were still unresolved. The problems lay in the presentation of specific issues like confidentiality, partner notification, and employment laws.

Many health care workers reported problems with what they perceived as the clash between protecting the patient’s confidentiality and protecting partners at risk, as well as family, community members, and employers. This unresolved debate is well known in HIV/AIDS circles, and yet training organisations were not prepared for the resulting difficulties when presenting this content. Organisations attempted to implement changes in both content and methodology, but without much success. Trainers argued that it seemed that there will always be those participants who accept the HIV/AIDS laws and those who do not. The reasons for this are complex. One, in a culturally and geographically diverse country like South Africa, there are often different traditional markers for the same ethical problem. That is, some rural groups are more community-oriented, while other urban groups are more individual-oriented. In looking at partner notification, for example, the former favour community or group human rights (the partner, the family and the community), the latter favour individual human rights (the patient). Two, one organisation also works on the belief that teaching HIV/AIDS ethics requires patience because, given the extensive history of human rights abuse in South Africa, participants are naturally going to be more sensitive to abuses on both sides of the debate, that is to both communities and individuals.

The teaching of ethics raised human resources problems.\(^3\) Few trainers wanted to present this content because of what was considered troublesome content and challenging delivery. As a result external trainers were sometimes brought in and subsequently there was no professional development of the organisation’s trainers in this particular field.

There were some positive reports about the teaching of ethics. First, trainers reported that some health care workers only truly grapple with this issue when they make their first ethical mistake. This is obviously not ideal because of the legal implications for the health care worker, but support, supervision, and advice structures were set up by some training organisations to assist the health care workers. Second, other health care workers were frightened into action by the legal implications of not following the law. This is also not the best reason for implementing policy, but it did seem to work. Third, organisations accessed resource material that health care workers could buy and keep on hand in order to guide good practise.\(^4\) Fourth, organisations encouraged programs like couple HIV counselling in which the issues of confidentiality and partner notification were explored. While there were problems with these programs, like the unwillingness of patients (particularly men) to present with their partners, some organisations trained counsellors who were successful in dealing with the ethical issues with the couple sitting together in the counselling room. Fifth, organisations made significant training contributions to areas like HIV/AIDS and employment, and HIV/AIDS and women.

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\(^1\) Trainers, ATICC, Focus Group, February 2001, Cape Town.


\(^3\) Manager, ATICC, Private Communication, January 2001, Cape Town.

\(^4\) For example, AIDS Law Project, HIV/AIDS and the Law (Johannesburg: University of the Witwatersrand, 1997).
Finally, various organisations played an important role in the HIV/AIDS training of ethics. For example, in May 1997, the AIDS Law Project and Lawyers for Human Rights published *HIV/AIDS and the Law*. This publication provided important information for health care workers: for example, checklists and recommendations for health care workers, with respect to partner notification. One group that played an important role in providing strong ethical messages was the Treatment Action Campaign (TAC). The TAC was launched on 10 December 1998. Its objectives were to "campaign for greater access to treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV treatments." Health care workers were aware of, and supported the TAC. Trainers reported that, from 1999 onwards, participants increasingly asked questions about the TAC and its objectives, and used the TAC as a reference point for ethical guidelines, treatment and policy development.

**Changing perception of training organisations**

Training organisations initially saw themselves as providing basic HIV/AIDS information and combating denial. Within two or three years, their advocacy and skills development roles came to the fore. By the mid- to late-1990s, training organisations began promoting and providing training for specific prevention and treatment strategies. For example, the Prevention of Mother-to-Child Transmission (PMTCT) program (1998), the Voluntary Counselling and Testing (VCT) program (2000), and the roll out of the antiretroviral (ARV) program (2003).

Trainers stated that expectations and demands from government, health sectors, and the public have increased from about 1998. Training organisations were now expected to be actively involved in a wide range of issues. For example, they needed to be involved in, or at least be aware of, issues like multisectoral HIV/AIDS responses with its focus on capacity/human resources development, care and support, children, conflict, education, democracy and governance, and economic development and microfinance. This increase in involvement led to staff specialisation, a high rate of reworking and turnover of material, and ongoing discussions about the presentation of material.

**Recruitment, training, and capacity development of trainers**

Many of the first trainers claimed that they ended up in HIV/AIDS training by default or because it sounded interesting. Almost all of these trainers entered the field in the late 1980s or early 1990s with no HIV/AIDS experience; some had training experience in health or human resources. These trainers were trailblazers, writing training material and developing courses from scratch. They had very few resources and almost no comparative training courses.

Trainers reported that strong leadership, that is, training managers and directors, played a vital role in providing strategic direction, not only to the training organisations, but
also to those attending the training courses. These strategic directions influenced training content and methodology and ultimately changed prevention and treatment practices.  

After five or so years of staff stability, there was a sudden turnover of staff, a pattern that has continued to this day. One manager described the early days as pioneering days when people stayed in their jobs because they felt a commitment to fighting the epidemic. The reasons for staff leaving after five years were that many felt that the field was becoming too complicated and politicised; there were too many players; there were no clear career development paths; and working with HIV/AIDS was too exhausting and overwhelming.

Some directors and managers were sensitive to these reasons for trainers leaving the field, and they made changes to ensure staff continuity. These changes included the establishment of: (1) career path development, (2) greater diversity in job descriptions, (3) increased networking and involvement in external task groups and committees, (4) management training, (5) advanced skills development, (6) coaching, (7) caring for the carer through interventions like staff support groups focussing on psycho-social and occupational stress, and (8) regular strategic planning. From an organisational development point of view, these organisations were coming of age. They were no longer small, limited organisations but growing and increasingly complex organisations. This growth suited some staff but not others. Since the late 1990s, most training organisations have specialised in various areas of HIV/AIDS like counselling, programme management, and treatment. By 2003, most organisations were employing at least double the number of trainers than they were in the early 1990s.

The final point deals with the recruitment of trainers. Since the mid-1990s, there has been a huge response to any advertised post for an HIV/AIDS trainer. Most organisations realised the importance of offering first language training, and thus made an effort to recruit suitable Xhosa, Afrikaans and English trainers. This made a huge difference to both the content and methodology employed by organisations. They now have parallel courses in three languages, and the content and methodology might all be slightly different from each other depending on the target training group. This resulted in more complex and interesting training, as attested to by training assessments and trainee feedback. Trainees have requested more first language training from trainers drawn from their own, or similar, communities.

Before moving on to the conclusion, an observation regarding a community acceptance model shall be made. Having completed an analysis of factors contributing to the shifts in content and methodology, it was noted that there is a useful model that helps explain community and individual responses to HIV/AIDS being spread as multiple epidemics. This is the Business Exchange on AIDS and Development (BEAD) Group’s Sequence of Changing Behaviour Model. This model argues that communities go through four stages – Invisible Epidemic, Awareness, Acceptance, and Behaviour Change – in changing their behaviour in response to HIV/AIDS.

First, Invisible Epidemic – In this phase, the community is not interacting significantly with the epidemic, and, for the most part, refuses to accept that HIV/AIDS exists. This phase is characterised by many conspiracy theories of why those in power want us to believe in a fictitious disease. Psychologically, this predictable and adaptive denial is usually associated

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1 In 1995, the AIDS, Training, Information, and Counselling Centre (ATICC) agreed to take on 4 of the 5 Provincial Key HIV/AIDS Strategies. ATICC managed the following strategies: Syndromic Management of STIs, Media/Condom Distribution, Lifeskills, and Counselling. ATICC made changes to their training content and methodology in order to incorporate these strategies into their courses. This initiative was successful in orienting health care workers to the key provincial strategies.

2 Manager, ATICC, Interview, June 1995, Cape Town.

with shock. That is, an individual or community will cope with the news of something negative by initially acting as if they have not heard about it. This is normal in that it provides the person or community time in which to filter and make sense of the shocking news. The problem arises when this denial becomes habitual and continues indefinitely. This can result in sudden upward trends in HIV transmission because the individual or community is practising unsafe sex. If one does not believe in the existence of a disease, why take precautions? The underlying assumption of this phase is “There is no problem.”

Second, **Awareness** – The community accepts that HIV/AIDS might exist, but they argue that it only exists in other communities, despite friends becoming ill and dying. These other communities are usually of different cultures, religions, or socio-economic groups. Implicit in this view is that the community in question deserves the presence of HIV/AIDS because of its difference. This phase, like the first phase of denial, contributes to increased transmission because of unsafe sex. The underlying assumption of this phase is “There is a small problem, and it exists in other communities.”

Third, **Acceptance** – The community now takes another step towards individual behaviour change by beginning to accept that HIV/AIDS is a problem. Acceptance and care in the community become more prominent. This phase, like the first two, sees no significant change in sexual behaviour, and transmission of HIV continues. The underlying assumption of this phase is “The problem exists, but not for anyone close to me”.

Fourth, **Behaviour Change** – The community is finally pushed to complete acceptance of personal risk factors and individual behaviour change. That is, the community can understand that anyone who is sexually active is at risk, despite what the person believes about the quality of trust in the relationship. For example, trainers reported that many participants, especially in the first few years of training, reacted strongly to the suggestion that persons in a marriage or a long-term relationship are, theoretically, at risk to HIV/AIDS. Trainers argued that some participants found it difficult to fully accept that there might be a past, present, and future risk of HIV transmission in any relationship. According to this model, this kind of response would place the participant in phase 3 (acceptance) rather than phase 4 (behaviour change). The underlying assumption of this phase is “HIV/AIDS is a serious problem, and anyone who is sexually active is potentially at risk.”

This model argues that very few communities get to phase 4 (behaviour change); at best, some individuals within communities might reach this phase. This conclusion, as disturbing as it is in terms of transmission rates, is backed up by what safer sex campaigners have referred to as the ceiling of those practising safe sex. That is, not every sexually active person will continuously practice safer sex. This model can assist training organisations understand the participants’ and patients’ acceptance of HIV/AIDS.

**Conclusion**

The historical analysis of HIV/AIDS training highlighted the significant shifts in content and methodology in the last fourteen years, and the factors contributing to these shifts. It also illustrates the complex interaction between the various contributing factors that influence the success of training programs. On a more fundamental level, this study shows the important role played by training organisations in the preparation and development of health care workers in the fight against HIV/AIDS.

Such analyses have important implications for practice and research. The high prevalence rates of HIV/AIDS in Southern Africa forced training organisations to work as quickly and efficiently as possible in delivering training to health care workers. Most training organisations have managed to establish innovative and practical training courses, and the history of how this was achieved can be used to assist organisations in other parts of the world.
in designing, delivering, evaluating, and managing training. The findings of this study are useful in guiding future HIV/AIDS training, as well as the importance of historical methodology to HIV/AIDS research. Various areas of HIV/AIDS research await the attention of historians.

The relationship between the HIV/AIDS training organisations and the provincial government is complex and unexplored. Further research is needed to investigate the sustainability of training organisations without the consistent support of central government. Related to this issue is the lack of historical research on the interaction between policy formation and training organisations. There are variations in how different health care workers are trained and interact with HIV/AIDS management. Further research is needed to examine the roles and experiences of specific professions working in HIV/AIDS, e.g. the current research being conducted on South African physicians treating people with AIDS.1 Also, it would be useful to conduct historical research of the experiences of those largely silent persons like home-based carers and mothers of AIDS orphans.

This study is limited in that one region in South Africa was analysed, and thus the results are not representative of the whole country. There are regions with significantly higher prevalence rates, e.g. Kwa-Zulu Natal, which might show different shifts and contributing factors. Similar comparative historical analyses would be interesting if conducted in other Sub-Saharan countries with high incidence rates, e.g. Botswana and Swaziland, as well as in countries elsewhere in Africa and the rest of the world with low, concentrated, and generalised epidemics.

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1 For example, the current research being conducted by Ron Bayer and Gerald Oppenheimer; authors of *AIDS Doctors: Voices of the Epidemic: Voices from the Epidemic* (New York: Oxford University Press, 2000).
A History of State Action: The Politics of AIDS in Uganda and Senegal

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Amidst the AIDS epidemic that is causing such destruction in Sub-Saharan Africa, two countries stand out for their progress in battling HIV – Senegal and Uganda. The two ‘success stories’ represent very different kinds of success – that is, one where early intervention kept HIV/AIDS under control and the other where concerted action in the context of a full-blown epidemic has seen early signs of stabilisation and even reduction of prevalence and incidence of the virus. This chapter examines the recent history of the fight against AIDS in both countries and suggests that central state action has been pivotal to the progress achieved to date.¹

The first two sections of the chapter examine contrasting patterns of the epidemic in the two countries and the gains made in fighting the virus. Section three explains the reasons why political leaders at the highest level of the state in both countries engaged early in the fight against HIV/AIDS. The fourth section examines the relationship between the state and societal actors, particularly religious groups and non-governmental organisations (NGOs) in launching the fight against HIV/AIDS. In the final section, I reflect on the lessons from these two ‘success stories’ in relation to the prescriptions for fighting the virus currently being promoted on the international stage.

Contrasting Patterns of the Epidemic in Uganda and Senegal

In Uganda the first cases of HIV appeared among people from the southwestern region of Rakai and it is believed that the virus established itself among high-risk groups there and in Kampala by the late 1970s.² Economic collapse and social dislocation, and new economic activities including the proliferation of the smuggling trade, contributed to the spread of the virus. While some young women turned to the sex trade, many more found themselves increasingly engaged in transactional sex as a matter of everyday survival. The spread of the virus seems to have followed the trade and communications routes from the African east coast to the centre of the continent. Long-haul truckers removed from home, with plenty of money to spend, led to the proliferation of bars and brothels along their routes as people sought income-generating activities. The increased sexual activities of men in this industry, both with multiple partners along these routes and with commercial sex workers (CSW) whose trade

¹ Research was undertaken in Uganda and Senegal during January 2003, while archival work continued over the next ten months.
was entirely unregulated, likely accelerated the spread of the virus. Sexually transmitted infections (STIs) were widespread and mostly untreated throughout these communities.1

The southwestern region also experienced the movement of armies, when Ugandan rebel fighters and invading Tanzanian forces overthrew the government of Idi Amin in 1979. Warfare and the movement of soldiers probably contributed to the spread of the virus through an increase in violence against women, trading sex for survival, increased levels of casual sex among multiple partners and unsafe parenteral and blood transfusion practices. The combined effects of social, political and economic disruption and war created conditions for the virus to pass from high-risk groups – truckers, soldiers and commercial sex workers – into the general population. The highest levels of infection were reported in urban areas, in rural areas along trade routes, and in districts beset by conflict and war.2

In Senegal, the virus was kept under control from the start by a combination of social, political and historical factors, as well as the particular epidemiological characteristics of the virus in West Africa. The first six cases of HIV were diagnosed in 1986. Senegalese researchers found this to be a different and less virulent strand of the virus, HIV-2, which may in fact have had an impact on slowing down the development of HIV-1, also present in the country.4 However, beyond this basic ‘epidemiological advantage’, a number of other factors were important to the control of the virus in the country. While Senegal remains among the poorest countries in Africa, it has experienced relative political stability since independence in 1960, a factor that has limited abrupt displacement among the population, allowed the maintenance of traditional and local institutions and organisations and kept violent conflict to a minimum.5

In terms of public health, there were two important moves made by the Senegalese state that probably played a pivotal role in limiting the spread of HIV later. First, the urban areas of Senegal, the key trading ports, had, since French colonial times, a highly regulated commercial sex industry. In 1969, the state passed legislation securing the legal status of prostitution. Commercial sex workers of 21 years and older registered with the state and there was a general surveillance and treatment of STIs among them from the early 1970s under the Bureau of Venereal Diseases. A national programme to fight STIs was also launched in 1978, well before the appearance of HIV/AIDS, initially to work mainly with CSWs. Second, the colonial government had established the first blood bank in 1943 and, as early as 1970, the state had launched a policy of safe blood transfusions, controlling for immunological and infectious risks.6


4 HIV-2 has been shown to be either less pathogenic or to have a longer latency period. Raymond A. Smith, ed., Encyclopaedia of AIDS: A Social, Political, Cultural and Scientific Record of the HIV Epidemic (London: Penguin, 2001), 327.


6 ONUSIDA, Groupe thématique ONUSIDA/Sénégal, Lutte contre le Sida: Meilleures pratiques, l’expérience sénégalaise (June 2001).
Certain social characteristics may also have contributed to preventing the spread of the virus. With 95 percent of the population Muslims, male circumcision is widespread and fairly strong mechanisms of social control over the sexual activities of young women were perpetuated despite significant negative economic pressures and rapid cultural change.¹

This then was the pattern of the epidemic in the two countries. By the mid-1980s, Uganda was experiencing a full-blown epidemic, while Senegal was positioned, as a result of early identification of the virus, to head off the epidemic.

**Achievements in Uganda and Senegal**

Although, Uganda’s fight with HIV/AIDS is far from over, progress in fighting the epidemic has stood in sharp contrast to many other Sub-Saharan African countries.² The first cases of HIV were identified in Uganda in 1983 and thereafter the number of reported cases expanded exponentially. Prevalence as measured by surveys of women attending antenatal clinics appears to have peaked in the early 1990s and declined through the decade, remaining stable from 2000 until now. Most spectacularly, in one urban surveillance site, Mbarara in western Uganda, prevalence was recorded at 30.2 percent in 1992 and had fallen to 10.6 percent by the end of 2001.³ Overall adult national prevalence probably peaked at about 15 percent in 1991 and had fallen to 5.1 percent by 2001 and 4.1 percent by year-end 2003.⁴ Especially important has been a marked decline in prevalence observed among young (15-19 year old) pregnant women.⁵

Significant achievements were made in the development of the ‘health infrastructure’ to deal with the epidemic. In 1987 Uganda’s Ministry of Health established four sentinel surveillance sites in hospitals with antenatal clinics, which expanded by the end of 2002 to 20, distributed to be representative of the whole country. Since 1986 the health services have also documented AIDS cases, which provide valuable insights for the fight against the virus, though the relatively small proportion of cases documented reflects the large number of people living with AIDS who still lack access to full health services.

By 2000, the Uganda Blood Transfusion Services (UBTS) claimed that screening was almost universal and blood safety increased to 90 percent. In 1990 the AIDS Information Center (AIC) was established to provide voluntary testing and counselling and expanded to four urban areas by the middle of the decade. As of 2000, some 400,000 people had been tested,⁶ still far too few. Since 1994, new programmes were initiated for the diagnosis and treatment of STIs. However, Uganda lags far behind Senegal in developing diagnosis and treatment.⁷

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⁷ Hogle, *What Happened in Uganda?*
There is considerable evidence that campaigns around individual behaviour have been effective. Women surveyed reported that condom use increased from 1 percent in 1989 to 16 percent in 2000, with the comparable figures reported by men increasing from 16 percent in 1995 to 40 percent in 2000. By the mid-1990s, two in every three people surveyed were able to cite at least two ways to protect against HIV. Some 57 percent of women and 64 percent of men reported that they had sex with one or fewer partners and the median age of first sexual encounter among girls increased by six months between 1989 and 1995.

In Senegal, since surveillance began, prevalence of HIV has remained at about 1 percent among pregnant women attending antenatal clinics and between 15 and 30 percent among registered CSWs at the sentinel survey sites, with an increasing trend over time. Prevalence observed among young women (15 to 25 years old) is three to four times less than women 25 years or older.

Senegal was quick to build on its established ‘health infrastructure’ to meet the challenge posed by HIV/AIDS. The World Health Organisation assisted Senegal in establishing its sentinel surveillance system in 1989. From surveillance sites in four districts, the system expanded to cover 10 out of the country’s 11 districts by early 2003. Surveys of ‘social behaviour’ were launched in 1997 and a ‘second generation’ surveillance system was launched in 2001, with the aim of expanding surveillance to all regions and which includes a survey of sexual behaviour among high risk groups including the military, migrants, seasonal workers and ‘mobile workers’ (truckers, fishermen, etc). When Senegal launched its HIV/AIDS campaign in 1986 it worked quickly to reinforce its earlier progress in securing blood supplies, ensuring what is claimed to be 100 percent safety in its blood banks and transfusions meeting international standards.

A behaviour survey conducted in 1997 by the AIDS Control for International Development/Sénégal drew on baseline data from 1993, and documented significant progress in promoting individual behaviour change: 90 percent of those targeted by educational programmes could identify at least two methods of prevention; between 1993 and 1997, the proportion of the population reporting having sexual relations with at least one casual partner was cut in half; in 1997, 70 percent of respondents said they had used a condom at their last sexual encounter with a casual partner; between 1993 and 1997 there was an 80 percent increase in the number of people who said they were able to gain access to condoms; and there was an increase over the period in the number of people who used the health services for STI treatment. Also there was a marked rise in the number of young girls who had not had sex and a rise in the number of boys who had used condoms consistently. Sales of condoms increased sharply between 1995 and 2000.

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1 For a less optimistic view of progress in condom use see, Uganda Ministry of Finance, Planning and Economic Development, ‘Uganda Participatory Poverty Assessment Process’ National Report (final draft) (Kampala: MFPED, December, 2002). This may be a reflection of the reluctance shown by President Museveni to emphasise condom use. The NRM published guidelines in the late 1980s that acknowledged condoms ‘can reduce the chance of getting AIDS’ but warned how ineffective they were. National Resistance Movement Guidelines for the Control of AIDS: Action for Survival (Department of Information and Mass Mobilisation, NRM Secretariat, printed with assistance from UNICEF, no date).


4 Interview with officials from Family Health International, established in Senegal since the 1970s, 23 January 2003.


6 ONUSIDA, Lutte Contre le Sida, 18-19.
National and Central Leadership

In analysing the progress made in bringing or keeping HIV/AIDS under control in Uganda and Senegal, it has become commonplace to celebrate the role of ‘political leadership’ in both countries. However, the ‘quality of leadership’ is an elusive factor. Some will be better leaders than others and leadership involves a complex set of determinants: intelligence and vision; charisma (the ability to inspire); rhetorical and organisational skills; openness to innovation; willingness to take risks, make hard choices and set priorities; accessibility of ideas and information; and luck. These factors of course played a role in both Senegal and Uganda, though arguably the personality of the leader was more important in Uganda and the nature of the leading organisation, the Parti socialiste, was decisive in Senegal. Analytically, there were three factors the provided the context for strong leadership in both countries.

First, leaders faced an incentive structure that meant they had nothing to lose and everything to gain from taking concerted action to fight the epidemic. Within months of taking power in 1986, Uganda’s new president Yoweri Museveni sent his first Minister of Health, Dr. Ruhakana Rugunda, to the World Health Assembly in Geneva where he announced the HIV epidemic facing the country.1 While some in Uganda recoiled in the face of international press coverage of the epidemic, by the end of his second year in power Museveni succeeded in uniting his National Resistance Movement government behind a full-blown campaign on AIDS. Early evidence that HIV/AIDS was pervasive in the armed forces was one reason Museveni was keen to act quickly. Furthermore, because Uganda’s economy was devastated by years of misrule and warfare, Museveni had more to gain from attracting international assistance to fight AIDS than he had to lose in tourism revenue and investment by acknowledging the extent of the epidemic.

UNICEF was present when Museveni launched the National Committee for the Prevention of AIDS, in Kampala in October 1986 and, in January 1987, the World Health Organisation (WHO) sent a mission to lay the groundwork for cooperation with the government. In February a WHO team assisted in drawing up a five-year action plan on AIDS, which was published on 2 April 1987. This laid the basis for a donor conference organised by the Ministry of Health and WHO in May 1987 and the launching of the first AIDS Control Programme in Africa.

In Senegal, the conditions under which President Diouf accorded high-level national attention to HIV/AIDS were very different.2 Senegal was not facing a full-blown epidemic when the government decided to act. Professor Souleymane Mboup and other university-based researchers had heard about the disease in 1983 and decided to undertake research in Senegal in collaboration with foreign academics. They discovered a virus in 1984-85 that was distinct from that found in Europe - HIV2 – and this discovery quickly gained international recognition for Mboup’s team. This had a pivotal effect on the course of action taken by the national government. When the first six cases of HIV were identified in 1986, Mboup went to the then Director of Health, where he joined with Dr. Ibra Ndoye who had been working on STIs among commercial sex workers. A triumvirate was formed between Ndoye, Professor Awa Coll-Seck who was working on infectious diseases with the Ministry of Health, and Mboup and they met with President Diouf.

The President was won over to the idea of a campaign very quickly. Mboup had already gained international fame and medical experts from the developed world were coming

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2 This is based on an interview with Professor Souleymane Mboup, Dakar, 24 January 2003.
to Senegal. Work on HIV/AIDS was seen as something that added value to, rather than detracting from, Senegal’s international reputation. USAID made it clear they would provide support. On 29 October 1986 the government launched the Comité National Pluridisciplinaire de Prévention du Sida (Multi-disciplinary National Committee for the Prevention of AIDS – CNPPS).

Second, in both countries, leaders based their decisions about HIV/AIDS on medical evidence. Senegal was fortunate to have within its senior medical establishment one of the world’s leading researchers on HIV/AIDS, Dr. Mboup. This was a reflection of the fact that the country had a significant tradition of medical research and teaching, an inheritance from Dakar’s position at the heart of French colonial Africa. The Ministry of Health included, in its senior ranks, highly skilled medical practitioners and researchers and, importantly, a relatively long-established programme of research and treatment of sexually transmitted infections (STI). The Socialist Party, which had ruled the country since independence, had a highly educated cadre at the centre, who respected the work of the Senegalese academic and scientific community, which itself was in close communication with the scientific community in France and Europe. When Mboup and his colleagues approached the President, Diouf was quick to launch state action.

In Uganda in late 1983, a team of foreign and domestic medical experts began investigating the first reports of a strange wasting disease, which local people had labelled ‘Slim’. Within two years, they had gathered conclusive evidence of the presence of HIV/AIDS. However, political authorities and officials in the Ministry of Health under the ‘second regime’ of Milton Obote were in as much a state of denial about AIDS as elsewhere in Africa. They were too preoccupied with holding on to power to undertake any serious action on HIV before the end of 1985. When Museveni’s National Resistance Movement came to power, the new president gave his support to the crusading young doctors and ordered the medical bureaucracy to make HIV/AIDS a priority. The donor community supported a huge research effort in which Museveni was said to have taken a personal interest.

Third, the impact of high-level political commitment to fight against HIV/AIDS and the all-out educational campaigns launched in both Uganda and Senegal created a situation where the epidemic was put beyond partisan politics. While Museveni faced many criticisms from opposition forces, all publicly admired the role he played in mobilising the nation around the epidemic and none put the government’s commitment to the fight against HIV/AIDS into question. In Senegal, even the radical change of administration in 2000, when Abdoulaye Wade became the first opposition candidate in the nation’s history to win the Presidency, did not alter the central government’s commitment to fight the epidemic. In fact, the team heading work on HIV/AIDS was retained in its entirety (while strengthened and encouraged to somewhat redefine its role). No one could occupy high office in either of these countries without demonstrating a commitment to continue the fight against the virus.

In Uganda, unity behind the HIV/AIDS campaign was achieved in part due to the overwhelming presence of President Museveni and his military organisation, given the context of the guerrilla war he had won. Museveni also left little room for open political

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3 See Putzel, “The Politics of Action on AIDS”, for a detailed account of the early work on HIV/AIDS in Uganda, including the role of foreign doctors who were an early casualty of a nationalist.
dissent once the NRM government adopted a policy.\(^1\) There were few families in the country, including the families of most major political actors, who were not affected by HIV/AIDS. In Senegal, it was the prestige of the country’s lead role in research on HIV/AIDS that helped build political consensus behind the campaign. Ib\(\)ra Nd\(\)oye, the public face of the campaign in Senegal, never joined a political party, ensuring that his work would not become partisan and maintaining his access to whoever held political authority.\(^2\)

**The state took the lead in mobilising society**

In both Uganda and Senegal state leadership was essential to making progress in the fight against HIV/AIDS, despite the dominant discourse advocating a major role for non-governmental, religious organisations and other non-state actors in the fight against the epidemic promoted by agencies like UNAIDS, the World Bank and the Global Fund to fight AIDS, Malaria and Tuberculosis (GFAMT).\(^3\) The central state was largely responsible for initiating action in non-governmental sectors in both countries, played a major role especially through ministries of health in both countries in promoting the infrastructure to deal with the epidemic, and laterally holds the key to problems of scaling up the response to the epidemic and ensuring that decentralised action actually materialises.

While Uganda and Senegal have had great success in involving both religious sectors and non-governmental organisations, essential to ensuring the development of multiple messages to effect behaviour change and to provide care for the ill, it was leaders of the central state who acted first to rally the nation behind the fight against HIV/AIDS. They had the knowledge and the connections with the international community, but most importantly, the authority to convince a diversity of social groups to organise around HIV/AIDS. The central government in each case encouraged existing associations to take up work on the epidemic and helped to form new organisations for that purpose.

The dissemination of information and education of the public at large has been of central importance in effecting sexual behaviour change in both countries. Like in most parts of the world, fostering open discussion about sexual behaviour touches on matters deeply personal and closely linked to specific moralities, values and religious beliefs. Early on in their campaigns political leaders in both countries saw the necessity of involving religious leaders and organisations. Not only were they needed to help influence the population, but governments needed to ensure that they would support, rather than oppose, efforts to discuss the epidemic. Because AIDS was initially linked in the rich developed countries to homosexual behaviour and injecting drug users, and even in Africa was initially linked to promiscuous sexual behaviour, enormous stigma was attached to the disease. No efforts of surveillance, prevention or care and treatment could be made without fighting stigma and religious leaders were recognised as playing an essential part.

In Uganda, President Museveni sought out leaders of the Christian community and urged his officials to avoid antagonising them. Initially, the President’s own opposition to the

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promotion of condoms helped to reassure Christian leaders. From very early on church leaders were invited onto the national committees charged with fighting the epidemic. One reason the traditionally conservative churches were won over to the coalition to fight the epidemic was the extent to which their own clergy and parishioners were touched by the epidemic. Inventive actions were taken, as when the star singer, the late Philly Bongole Lutaaya, came out openly as HIV positive and organised a concert in the Namirembe Cathedral, in the very early years of the campaign. People took the word of clergy members to heart due to their positions of authority in communities. Like in politics, crucial to the mobilisation of the religious groups was the early involvement of respected leading members of the clergy, like the late Bishop Yona Okoth who provided the space within the church for AIDS activists to operate. Canon Gideon Byamugisha played an enormous role in breaking down prejudice both within the church and in Christian communities, when he revealed that his wife had died of AIDS and that he discovered after her death his own HIV positive status. Church organisations have provided subsidies to people to have their status checked and have trained clergy and lay members in counselling. They could reach far into the rural communities, perhaps where even the NRM could not.

In Senegal, President Diouf and leaders of the National Committee also worked hard to involve traditional religious leaders of the majority Muslim community, which makes up some 95 percent of the population. Traditional religious leaders command enormous influence in the country. The government began by encouraging a survey among religious leaders, carried out by an NGO, which found that most had very poor information about the virus. On this basis a process of negotiation was undertaken. The Muslim NGO, Jamra, (not known for its tolerance having waged Islamist campaigns against drugs and ‘perversions’ in the past) worked with the highest Islamic officials in the country and the major schools of Islamic thought. The most controversial issue, as in Uganda, concerned the use of condoms and like in Uganda, religious leaders did not support the use of condoms, but were won over to a position where they would not oppose either government or private sector efforts to promote condom use. A clear example of the way multiple messages were employed to achieve behaviour change came with the publication of Guide Islam et Sida, which while disseminating the basic facts on the epidemic, emphasised how Islamic teaching could help in preventing the spread of the virus. Religious leaders became particularly involved in treating those succumbing to AIDS. The Catholic Church came on board much later, finally participating in a conference in Dakar organised by the NGO Sida-Service in 1996 (though Sida-Service itself was involved before this).

International donors and international religious communities played an important role in winning over local churches and mosques. The World Council of Churches produced a pamphlet as early as 1987 entitled What is AIDS?, which had an important influence in local

3 Interview, Canon Gideon Byamugisha, 7 January 2003.
6 As late as 1994, Charles Becker berated the silence of the Church. ‘L’église et le sida en Afrique’, Afrique & Parole 39 (February 1994), 2-4; also in Perspectives missionnaires 27, 66-76. In Uganda the Church joined the multisectoral organisations only in 1995.
church circles in Uganda. USAID was instrumental in assisting church and mosque leaders to organise a conference in 1991 to learn about and commit to the fight against HIV/AIDS.

Some religious organisations have been major providers of health care and education in the absence of public authorities’ ability to do so. While claims have been made that religious organisations have provided health care more cost-effectively than public organisations (a ‘religious premium’ on lower wage costs), some of these tend to evaporate when it is noted that the government wage costs include a lunch allowance, as one consultant pointed out. There is a tendency to turn necessity into a virtue in this respect, particularly with aggressive faith-based initiatives in some of the donor countries.

In both Uganda and Senegal, as some religious AIDS activists themselves said, the state had to take the lead not only to ensure a plurality of faith groups could be involved, but also to ensure that the messages of these groups came as supplements to secular public health messages and information. Some secular activists felt uncomfortable that government was putting its name to publications, which while constructive in mobilising members of religious communities, at the same time in citing the Qu’ran still spoke of God’s instruction, ‘don’t go anywhere near sex outside of marriage. In reality this is a depraved act and a detestable road’ adding ‘If men transgress this divine warning, depravity will develop on land and sea as a result of their own sins’. Others suggested that it was not enough to get traditional and religious leaders not to oppose the HIV/AIDS campaign and government promotion of condom use, but felt that secular government and non-government leaders needed to put pressure on the religious sector to discard old taboos and prejudices.

As with religious organisations, the associational sector (NGOs, community based organisations and professional associations) has been a pivotal player in both Uganda and Senegal’s HIV/AIDS campaigns, particularly in getting messages on behaviour change to communities and in providing counselling and care and treatment to HIV positive people and people living with AIDS. However, the central state was pivotal, not only in creating the space for the associational sector to act, but in initially mobilising the sector around HIV/AIDS.

In Uganda, despite the hegemony of the National Resistance Movement on the political scene, President Museveni and his cadres saw the importance of NGOs to their general reconstruction efforts after coming to power in 1986 and created a favourable environment for them to grow. The international donor community was instrumental in providing funding for the NGO sector from the earliest days of the Museveni regime. In 1988, The AIDS Support Organisation (TASO) was founded by people living with HIV/AIDS and members of their families. TASO was instrumental in the elaboration of the ‘multisectoral approach’ in Uganda and a pioneer in promoting voluntary counselling and testing as well as piloting the use of antiretroviral therapies in the country.

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2 Christian fundamentalist groups in the United States have become particularly active lobbyists in relation to foreign assistance programmes in the HIV/AIDS sphere.
3 Interviews with activists in Kampala and Dakar, January 2003.
In Senegal, President Diouf’s Socialist Party reached out to the associational sector to educate organisations about HIV/AIDS and to encourage the formation of new organisations to deal with the epidemic. International NGOs contributed as well, with the group, Environment et développement en Afrique (ENDA) playing a central role right from the start, working with government from the top-down to establish associational activity. NGO activists themselves remember how it was the state that called associations together, that met with local women’s organisations and told them about HIV/AIDS and urged them to develop activities. Once organisations like the Society for Women and AIDS in Africa (SWAA) were established they worked on a genuinely voluntary basis with little financial support from the state or international sources during their first decade. By early 2003 there were hundreds of associations involved in HIV/AIDS work, many of which were affiliated to the International Council of AIDS Service Organizations (ICASO), whose president locally sat in the CNLS and whose regional headquarters was established in Dakar hosted by ENDA.

There is a particular dimension of NGOs’ role in HIV/AIDS work, which is likely to ensure continued mobilisation and activity within civil society, unlike in many other dimensions of NGO work – that is, the organisations of People Living with HIV/AIDS (PLWH). Sustained bottom-up activity is now being promoted by these organisations. The promotion, involvement and financing of organisations of PLWH is pivotal to all dimensions of action, from prevention through care and treatment, including the many difficult issues related to rights and ethics.

Nevertheless, the central state’s role remained strategic. In both Uganda and Senegal, the campaigns against HIV/AIDS were launched in an environment of health service reforms involving both the decentralisation of service delivery and the privatisation of service providers – or at least the arrival of private providers to compete with those in the public sector. The Global Fund and the World Bank, as well as many bilateral donors, especially USAID, were deeply involved in the development of decentralised delivery of resources for HIV/AIDS.

In Uganda, President Museveni was adamant about pushing resources out to the districts even if it meant some funds would be lost. Early efforts by the World Bank to transfer funds directly to the district level floundered and project funding reverted to the Ministry of Health. However, when the Bank launched its Multi-country AIDS Program, new efforts were made to set up District HIV/AIDS Committees, mirroring the structure of the national AIDS commission. Capacity at the district level remained woefully inadequate, however, especially as decentralisation proceeded very rapidly. Despite aspirations to develop a multisectoral approach at the local level, this seemed often to exist in name only.

Senegal has a long experience of highly centralised government. However, in 1991 the government created a district level health system, with a further transfer of authority to local governments in 1996. By the year 2000, roughly 44% of HIV/AIDS funding went to the centre, 15% to the regional level and an impressive 41% to the district level, which demonstrated a genuine effort to ensure money reached the operational level. The pattern of the distribution of funding, however, was determined by donor zoning requirements rather than relative needs between the districts. This was a problem that appeared to be shared in

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1 Interview, Aminata Touré, UNIFEM, Dakar, 23 January 2003.
2 Interview with Mbaye Maniang Diagne, Valérie Mouley Omar and Nafi Sar, SWAA, Dakar, 24 January 2003.
3 ICASO was later replaced by COSSEN (Conseil des organisations de lutte contre le Sida au Sénégal), which was closely linked to CNLS and major community organisations, like ENDA, undertook successful action to get a hold of more resources. Personal communication from Charles Becker, November 2004.
4 Interviews with Sam Okware and Elizabet Madra at the Ministry of Health, 9-10 January 2003.
Uganda, underlining the need for central government to establish clear criteria so that funds could reach districts on the basis of need and epidemiological evidence rather than due to particular political connections.

In Senegal the central state had to play a key role in training local actors and ensuring they had the financial resources to carry out their work. As of 2000, apart from Dakar, no regions received funds for HIV/AIDS from local authorities. However, over the next few years USAID began working with local government units to provide a ‘full package’ of support for HIV/AIDS related work. Interestingly it required local governments to raise tax revenues to finance, at least partially, campaigns against the virus as a condition for funding, something also advanced by the World Bank’s MAP.¹

In both countries, health officials – even those deeply involved with, and supportive of, decentralisation measures – were worried about the rigid requirements imposed by the Bank and the Global Fund in terms of decentralising resources. This is because capacity at local levels of government remained terribly unequal and generally inadequate. Senegal’s experience seems to demonstrate that appropriate medical expertise can best be developed first at the centre and, with training and increasing resources, be incrementally devolved to district and sub-district levels. In early 2003, the NGO community itself, generally supportive in principle of efforts to get resources out of Dakar and down to the communities, argued that the framework offered by the Bank and Global Fund was inadequate (and was hardly discussed with the NGO sector).² One NGO leader said that surveys conducted demonstrated that HIV/AIDS was fourth or fifth on the agendas of local governments. Interestingly, he argued that a strong centre was needed to demonstrate to local governments why AIDS is important. At the same time, he argued for national level involvement of NGOs to ensure that resources would actually reach the associational sector at the local level.

In Uganda, when Museveni came to power in 1986, what had once been an efficient and well run health service had long since virtually collapsed. The issue was not one of privatisation, as the narrow base of health service delivery after years of war, political instability and economic decline had wrecked the public sector. What health care existed was almost entirely private. NGOs and church related organisations were encouraged to deliver health care as efforts were made to reconstruct the public sector. Cost-sharing (patient fees), long practiced at least informally through the payment of bribes and the like, was tolerated by the Ugandan government but never endorsed as policy by Museveni. In 2001 it was abolished in what some claim was a blatantly political move by the President to gain support before elections. While the abolition of cost-sharing led to some short-term difficulties in supplying adequate drugs to meet demand, evidence emerged pointing to an expansion in the use of government health services.³ Others suggest that cost-sharing was never a deterrent to the use of public services, but rather people were deterred by ‘misconduct on the part of health workers, as well as perceived poor quality of service, including the dispensing of pain killers no matter what ailment one was suffering from’.⁴

Clearly, there are compelling reasons in the fight against HIV/AIDS to have an integrated health system, at least as a goal. In Uganda, it was the fight against AIDS which

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¹ Interview with USAID officials, Kampala, 8/01/2003.
² Interview with Baba Goumbala, Alliance Nationale Contre le Sida, Dakar, 24/01/2003.
provided the opportunity to develop a centralised system for monitoring disease.¹ The requirements of surveillance of the epidemic, of providing experienced counselling and testing facilities, of ensuring safe blood supplies and parenteral practices, of treating opportunistic infections and developing antiretroviral therapy in the future, all militate towards greater integration in approaches to public health, rather than dispersal to systems of private providers.

**Conclusion: Assessing ‘success’ in light of international prescriptions**

Identifying Uganda and Senegal as ‘success stories’ in the fight against HIV/AIDS, in no way means that the battle to control the epidemic is over in either country. Uganda still faces a high HIV prevalence rate and in those parts of the country still at war we have no knowledge of how high that is and very little if anything is being done to control the epidemic. In Senegal two particularly worrying trends have emerged: first, a declining trend of HIV-2 has been matched by a rising trend of HIV-1, and while women once constituted a minority of those infected, they now are the majority.² In both Uganda and Senegal efforts to promote behaviour change have remained largely directed at individual behaviour. While significant progress has been made in dealing with behaviour in the armed forces in both countries, much less has been done to address the institutional barriers blocking change in the behaviour of other groups, addressing structural features like women’s position in society or patterns of migration to secure livelihoods.

In the HIV/AIDS programmes of both countries, ‘care and treatment’ has been recognised as the biggest challenge, yet, in both, the means to deal with mounting numbers of People Living with HIV/AIDS are woefully inadequate. Despite education campaigns, stigmatisation remains a major problem in communities and workplaces. Outside of hospitalisation, care and treatment is being carried out by the non-governmental sector, which faces huge deficits in terms of skilled personnel and funds.³

It must also be said that even in these ‘success stories’, very little has been done to address the long-term causes and impact of the epidemic. This obviously poses challenges far beyond the capability of single nation-states and it is unlikely that substantial progress can be made in this area without a transformation of the international efforts to fight the epidemic. Thus far, international agencies have focused much of their attention on attempting to promote campaigns for individual behaviour change in the countries hardest hit by HIV/AIDS. With the development of antiretroviral therapy and the access that the wealthy can gain to these drugs, the basis for the broad political coalitions that were built to fight HIV/AIDS in both countries may be weakened in the future.

The international community has advocated a model of response to HIV/AIDS, which is centred on developing a ‘multi-sectoral’ effort to fight the epidemic, involving all branches of government and a wide cross-section of religious and non-governmental organisations. While this orientation recognises the social character of the epidemic and rightly breaks from thinking about HIV/AIDS as a purely medical problem, it is important not to lose sight of the key role that the state has played in successful battles against HIV/AIDS.⁴

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¹ Jim Holt of the World Health Organisation in 1987 said, ‘We are using AIDS in order to establish an effective surveillance system for Uganda, and one that will operate for measles, cholera and other such diseases as well’ (cited by Hooper, 1990, 254).


³ Interview, Baba Goumbala, Alliance Nationale Contre le Sida, Dakar, 24 January 2003.

The kind of ‘health infrastructure’ required to mount a battle against the epidemic - including establishing surveillance systems, providing clean blood supplies, securing parenteral practices in health delivery, providing adequate testing facilities, ensuring treatment of STIs and regulating the activities of commercial sex workers – requires the full involvement of the medical profession and the consolidation of the public health system. This can only be done, in the medium to long term, through the consolidation of central and local organisations of the state.

It is clear that a central state response only works where the state’s reach extends deeply down to local communities. In different ways, in both Uganda and Senegal, the central state has incorporated local and traditional leaders in systems of hierarchical authority. There is some evidence in both countries that local communities, which had little access to income generating activities of any kind, engaged in the fight against the epidemic as a means of gaining access to funds and employment opportunities provided by the state for that purpose. In other words, the state’s leverage in promoting successful AIDS campaigns was related to the impoverishment and dependence of local communities. Effective behavioural change, in rural areas at least, may have been achieved through the reinforcement of control over young women by traditional authorities.

In Senegal, the government’s early response is one reason why the epidemic was arrested in its tracks. While the Parti socialiste was often criticised for over-centralisation and, while much of the discourse about achieving the kind of behavioural change that is necessary to slowing transmission of HIV/AIDS is geared towards mobilising ‘civil society’, it was the Parti socialiste’s centralist character that allowed it to reach down through the associations to every corner of the country and that was responsible for the early awakening of the nation to the danger posed by the virus. In a similar way, in Uganda, the centralist authority of the National Resistance Movement, and the military organisation on which it was based, also made quick dissemination of the message about HIV to every village possible. It was Museveni’s military organisation that in 1988 implemented the country’s first national sero-survey.

The benefits of the central state’s role on all these fronts clearly can best be achieved where leadership is provided by a political party, rather than dependent entirely on the beliefs and abilities of individual leaders. In Senegal, the culture and programme of the Parti socialiste was more important to positive action than the person of President Diouf. In Uganda, and in Senegal since the election of Wade, action on HIV/AIDS has been determined by the individual leadership of populist presidents. To be sustained over time gains must be institutionalised both within party programmes and within the organisations of the state. One of the most precarious aspects of the many successes Uganda has achieved in development since 1986 is the overwhelming reliance on the personal attributes of the President on one hand, and the role of foreign donors on the other. Moves by Museveni in 2003-04 towards multi-party competition potentially appear as an antidote to over-reliance on the person of the

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3 The most articulate members of the NGO community recognise this. Interviews with Aminata Touré (UNIFEM) and Baba Goumbala (ANCs) in Dakar, January 2003.

4 However, the NRM was slow to develop cooperation with the National Committee for the Prevention of AIDS. See Putzel, “Politics of Action on AIDS”.

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president and may open the way to greater institutionalisation of gains both within the NRM and within state organisations.

While a multi-sectoral approach and the involvement of a diversity of social organisations and associations was essential to progress in both countries, this was made possible through strong central state leadership. Of course, in countries where there is an absence of strong central leadership, the burden of organising a response to HIV/AIDS must be borne by organisations in society. But just as NGOs and community based organisations can never provide for the military security of a country, neither can they provide for security from an epidemic like HIV/AIDS. It is difficult to imagine how sustained progress can be made in protecting a population against the virus if central leadership is lacking.
Part Five

Debating HIV/AIDS
“Scramble for Cameroon”  
Atypical Viruses and Scientific Zeal in Cameroon (1985-2000)

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The history of scientific and medical mobilisation against AIDS remains, to a large extent, a history of the centre. Even the most inspired studies are limited to the reassuring scene of major western cities – a scene which is certainly one of conflict and which is “impure” but one which is well and truly confined. The peripheries of the rest of the world, and Africa in particular, appear only in the wings as sinister places, in a state of permanent waiting which is in strong contrast to the scientific and militant turmoil of the centre. However, even if it is only because of the enormous impact of the epidemic on the continent, Africa has functioned not only as a more or less “pathological” background to research on AIDS but has managed to occupy, on a scientific, political and even industrial level, the very centre of western experience of AIDS. Ignoring this presence would be tantamount to missing an entirely new process of globalisation, which accompanied the emergence of scientific issues of the “South” at the outset, but which did not leave the western “centre” unscathed – think of France whose “national grandeur” on the global AIDS scene is largely due to her symbolic and material deployment in Africa, indeed to the institutional and demographic signs of her former colonial links. This is why it is important, in the style of recent attempts of the so-called “postcolonial history of the sciences” to overturn the perspective: interpret History within the parameters which it has set itself, interpret, especially and constantly, how the periphery informs and reforms the centre.


2 Cristiana Bastos’ work is a notable exception. It simultaneously considers the heterogeneity of the scientific scenes of the North (where “AIDS doctors”, firms and activists cross paths) and the constitution of a transnational field whose players and institutions reproduce this heterogeneity whilst at the same time coupling it with movements and asymmetries of the Centre-Periphery type: Cristiana Bastos, *Global responses to AIDS: science in emergency* (Bloomington, Indiana University Press, 1999).

3 The Pasteur Institute and the Agence nationale de recherche sur le sida (ANRS), two French “cultural exceptions”, insist on their specific relations with francophone African countries. Moreover, the presence of African migrants, in the Parisian region in particular, contributes to the magnitude of the HIV/AIDS epidemic in France, as compared to other European countries.

In this spirit I shall attempt to write a global history of the research into AIDS in Cameroon. This does not mean that I shall simply concentrate my remarks on a limited locality in order to re-interpret a global context, by “changing the angle of the magnifying glass”: I shall rather offer detailed and precise discussions of the global integration of Cameroonian research by examining the common devices – institutional, social, technological – which transcend international boundaries without, of course, losing sight of the unequal relations which they integrate and re-orientate. By its very form, this article is part of this project, by conceiving of itself not as an isolated “case study” from which one could draw, because of its anonymity and abstraction, a few generalities concerning “African science”, but by attempting to be a narration, a true story which is fully integrated into the larger story – scandalous or glorious – of the Big Science and its “races”.

The main reason for Cameroon’s integration into the international field of AIDS was that it was “favourable terrain” for research into the AIDS viruses. As Franco-American controversies concerning the isolation of the HIV-1 virus in 1983 have shown, the “race for the viruses” jeopardise significant interests, whatever the geographic area: whereas the identification of a virus represents a source of knowledge and recognition for academics, for pharmaceutical firms this identification, strengthened by the law of intellectual property, signifies the immediate and remunerated reward of diagnostic tests. These stakes which are reduced by the scale of the AIDS epidemic, have, since 1984, affected Africa which decades of colonial and post colonial research have shown to be a terrain rich in “biological unknowns” and “health threats”. Apart from epidemiological surveillance, virological work and the related diagnostic questions have thus constituted from the first – albeit late – distribution of antiretrovirals at the end of the 1990s, the main scientific activity in Africa in the field of AIDS, certainly in terms of media and academic visibility.

During the 1990-2000 decade more than ten international teams have established research projects in Yaoundé, the administrative capital of Cameroon. Explicitly geared towards the collecting and analysing of retroviral colonies circulating in Cameroon, these projects have rallied private companies, international institutions of health surveillance and university laboratories in France, Germany, Belgium, Japan and the United States. This unprecedented craze for Cameroonian biological material – in this case the blood samples of patients and monkeys – has sometimes taken the form, in the words of the researchers themselves, of a “race for collecting”: the competitive extraction of “raw scientific material” enhanced by molecular analyses in laboratories of the North. As a result of the conflicts to which it has given rise, it can be said that this race had become the scientific version of the “scramble for Africa” which, in the past, opposed colonial powers. Importantly, what political pundits call “tactics of extraversion” have superimposed themselves on and adapted themselves to the “logics of extraction”. Fred Eboko, in his analysis of policies of the fight against AIDS in Cameroon has shown that foreign scientific zeal and the structural

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1 For this research I have consulted the (mostly unclassified) archives of the Pasteur Centre of Cameroon in April and May 2002, with the assistance of its director, Jocelyn Thonnont. They include the annual reports of activities of the Pasteur Centre. I also made use of the archives of the OCEAC General Secretariate with the assistance of Mr Frédéric Berteau and Mr Georges Souloulat. The full collection of the OCEAC technical reports are kept in these archives. More than forty open-ended interviews have been conducted with various role-players in Cameroon, in several European and American research institutions (Institut Pasteur, IRD, CDC), as well as with retired development workers. Some interviews are only quoted anonymously.

2 On this point, one should, of course, consult Mirko Dr Grmek, Histoire du sida, 3rd ed. (Paris, Payot, 1995).


dependence of the health system and research in Cameroon have provided a resource for certain local players: a handful of Cameroonian academics have learnt, with decided talent, how to exploit and even create this unequal relation. “Gatekeepers”\(^1\) of a favourable site, these researchers have been the catalysts and main local benefactors of an international infatuation for Cameroonian territory. I propose putting this infatuation into its historical perspective and explaining the scientific and biotechnological stakes of the study of the Cameroonian virus.\(^2\)

The unobtrusive beginnings of research into AIDS in Cameroon, 1984 -1988

When the first cases of AIDS were diagnosed in Cameroon at the beginning of 1985, the field of medical research was marked by the ascendancy of two institutions, the Pasteur Centre of Cameroon (CPC) and the Organisation for the Control and Fight Against Great Epidemics in Central Africa (OCECA). Situated in the heart of the administrative centre of Yaoundé, their massive buildings, close to the Central Hospital, embody the heritage of French scientific presence. In 1985, “health hill” accommodated, in fact, many French volunteers, doctors or researchers who, each in his or her own way, followed in the footsteps of French colonial doctors who have been in Cameroon since 1916.\(^3\)

The Pasteur Centre rapidly became a privileged place for the study of the new pathology. Its large laboratories for medical analyses which were responsible to the Cameroonian Ministry of Health were managed by French military doctors. Linked to the Pasteur Institute in Paris since its founding in 1959, the Pasteur Centre also undertook some research work notably on hepatitis B, under the aegis of the expatriate managerial staff, the Pasteuriens. Already in a position to diagnose opportunist infections and lymphocyte counts, the virology service received the first Elisa tests, “ELAVIA”, in June 1985 which had been marketed by Pasteur Institute Production and perfected the use of the first Western Blot test at the end of 1985. Four cases were immediately positively identified by the Centre’s virologist, Jean-Paul Durand.\(^4\)

Together with OCEAC, the Pasteur Centre led the investigations into the seroprevalence of the virus responsible for AIDS\(^5\) in July-August 1985. Since its creation in 1962, OCEAC had also accommodated French military doctors; its initial mission was to conduct and coordinate, at regional level, the work carried out by mobile teams of doctors, the celebrated flagship of French colonial medicine. True to their vocation of men on the ground, the French doctors of OCEAC formed a tandem with the Pasteuriens and multiplied the

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\(^1\) “Gatekeepers”, an expression used mainly by Frederick Cooper. See F. Cooper Africa since 1940: The Past of the Present (Cambridge, Cambridge University Press, 2003).

\(^2\) This article is a shortened and reworked version of the second section of Guillaume Lachenal’s DEA dissertation, “Le Centre Pasteur du Cameroun: trajectoire historique, stratégies et pratiques de la recherche biomédicale en cooperation (1959-2002)” (Dissertation for the DEA [diploma taken before completing a PhD] in Epistemology, History of Sciences and Technologies, University of Paris 7 Denis Diderot, 2002), 173 pages. Some parts of this article were presented at the conferences of the Society for the History of Technology (SHOT Annual Meeting, 16 October 2003, Atlanta, USA) and the Society for the Social Studies of Science (4th Annual Meeting, 28 August 2004, Paris, France.) The author thanks Charles Becker for his advice and re-reading of the text, as well as Anne Marie Moulin, Fred Eboko and Roland Waast.

\(^3\) Cameroon is an ex German colony (Kamerun) which, after the First World War, was placed under French and British rule (with the status of territory under the mandate of the League of Nations and, after 1945, territory under protection of the UN). Most of its territory (with the exception of the western part of the country) was governed, up until independence in 1960, as though it were a French colony.

\(^4\) Guy Garrigue, Rapport sur le fonctionnement technique du Centre Pasteur du Cameroun, 1984-1985, 120. Archives of the Pasteur Centre of Cameroon.

\(^5\) Named LAV/HTLVIII in 1985, in reference to the “joint” discovery of identical viruses by the teams of Luc Montagnier and Robert Gallo, the virus was renamed HIV as of May 1986.
investigations into AIDS between 1985 and 1988 (seven in Cameroon in two years, twenty-
two in total\(^1\) over the entire sub-region\(^2\)) alternating polls amongst the general population
(cluster investigations which consisted of visiting every home in a road chosen at random)
and studies amongst “populations at risk”.

The initial results, published at the end of 1985 in a report concerning the activities of
the Pasteur Centre were “less alarming than in other African countries”\(^3\). Those which
followed, reported extremely low levels of people being HIV positive: a 1986 study on blood
samples taken at the Pasteur Centre and the PMI found a 0% level of HIV positive people. A
total of fifteen cases of AIDS was counted in June 1986\(^4\). OCEAC’s epidemiologists ended
their summary of cluster investigations carried out in the sub-region with a reassuring
conclusion:

The spread of HIV in Central Africa is clearly confirmed.
However, the levels of HIV prevalence (from 0 to 4.6%) are much lower than those which were
recently announced by some influential information media. […] It is therefore appropriate to lessen
those fears that the publication of the preliminary results obtained in Central Africa by the study of high
risk groups (…) may have engendered.
The estimation of HIV prevalence found in the samples […] which were selected in a totally random
fashion seems to be a good way of avoiding the over estimation of the phenomenon\(^5\).

In this context, the international visibility of Cameroon was limited. The attention of
the first AIDS specialist in Africa was, at this time, concentrated in countries such as Zaire,
Uganda and Rwanda which were affected by the disease. In particular, following on the
discovery of numerous cases of AIDS amongst migrants from Zaire to Belgium, the city of
Kinshasa attracted the first large scale researcher from 1983: this was followed by the “AIDS
Project” epic which was put in place at the Mama Yemo Hospital by academics from the
Center for Disease Control of Atlanta (CDC) and the Institute of Tropical Medicine of
Antwerp\(^6\). The Pasteur Institute of Paris, another leading institution in the field, concentrated
its efforts in Africa in its Bangui venture where, in October 1985, the main researchers into
AIDS in Africa gathered to elaborate a clinical definition appropriate to the African context,
the famous “WHO definition of Bangui”. Finally, Dakar asserted itself as an emerging site on
the map of African research: from 1985 Souleymane Mboup, a pharmacist at the Le Dantec
Hospital in Dakar collaborated with American and French researchers from Harvard and
Tours in notable work on the Senegalese HIV epidemic (see below).

Cameroon was therefore somewhat abandoned, as a Cameroonian doctor recalls:

Why go to a country where we had perhaps to wait for two years before we had about a hundred
patients whereas in other countries where there was a high prevalence, one could have as many
(patients) in 2-3 months?\(^7\)

The scientific (and media) exploitation of research carried out in Cameroon, although
naturally limited, was a Pasteur monopoly during these early years. Guy Garrigue and Jean

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\(^1\) The reports of investigations are combined in the technical reports of the OCEAC, and were consulted in Yaoundé (Offices of the OCEAC) in April 2002. They are filed under RT/OCEAC/SG/SES Nr 559 to 658.

\(^2\) That includes Gabon, Equatorial Guinea, Chad, Central African Republic and the Congo.

\(^3\) Guy Garrigue, Rapport, 1984-1985, 120.


\(^7\) Interview with Léopold Zekeng, Yaoundé, 29 avril 2002.
Paul Durand presented their findings at the International Conference on AIDS in Paris in June 1986, then at the WHO Regional Conference on AIDS in Brazzaville\(^1\) in November 1986. They were also locally active with Guy Garrigue appearing in the Cameroon Tribune, the national daily, in November 1985\(^2\) and Jean Paul Durand chairing a round table discussion on the subject at the Faculty of Medicine (the CUSS). In June 1987, Jean Paul Durand presented a poster “AIDS in Cameroon”\(^3\), on behalf of the Pasteur Centre and OCEAC, at the International Conference of Washington. Not a single Cameroonian signed this presentation.

The emergence of Cameroonian researchers

Despite this, since 1986 Cameroonian researchers have participated in epidemiological investigations carried out by the Pasteur Centre and OCEAC. Professor Lazare Kaptue is one of them. A serologist who was trained in France, former pupil at the Pasteur Institute, Lazare Kaptue, by virtue of the fact that he was a professor at the CUSS and director of health, became, in 1985, one of the main figures in the Cameroonian medical field. After having created a follow-up committee on AIDS in the Ministry of Health, he rapidly became, in the Cameroonian health ranking system, “Mr AIDS”.4

At the time, when it all began, not a single Cameroonian doctor wanted to work on AIDS [...]. I was obliged to work with AIDS because, as director of health, I had to set an example. [...] It wasn’t deliberate, it came about because of the situation where everyone was afraid. I was the very first person to become involved in this fight, here in Cameroon [...].5

Local specialist in an illness which terrified people, Professor Kapute did not benefit from the material means offered by the Pasteur Centre, nor from its links with the Pasteur Institute – producer of AIDS detection tests. Towards the end of 1985 he obtained, with difficulty and after the Wellcome laboratories had refused them, kits from the Behring laboratories for use in his CHU service which housed the blood bank. Léopold Zekeng, a young specialist in medical biology who trained in Dakar – together with Souleymane Mboup – as well as in France, was appointed to this service as his first post in Cameroon; his specific brief was the serological detection of HIV which began in 1986 at the blood bank.

The field of research into AIDS in Cameroon was to be drastically reorganised at the end of 1987 by the creation of the National Programme for the Fight Against AIDS, on the official instructions of the WHO\(^6\). Lazare Kaptue quite logically assumed the directorship of the National Programme which effectively came into action in October 1988 with the launch of the Medium Term Plan of Action which made provision for epidemiological surveillance as well as psycho-social studies. In collaboration with OCEAC, a “system of

\(^{1}\) “Le sida au Cameroun”, paper read at the regional conference on AIDS organised by the WHO, Brazzaville, 11-13 June, 1986, also published in Guy Garrigue, Rapport, 1985-1986, 94 and seq.
\(^{4}\) For a more complete picture of the role of Professor Lazare Kaptue in the fight against AIDS, see Fred Eboko, “Logiques et contradictions internationals dans le champ du sida au Cameroun”, Autorepart, 12 (1999), 123-140; Fred Eboko, “Pouvoirs, jeunesse et sida au Cameroun” (doctoral thesis in Political Sciences, University Denis Diderot – Bordeaux II, 2002) 490 p.
\(^{5}\) Interview with Lazare Kaptue, Yaoundé, 6 October 2003.
\(^{6}\) For a general study of the history of the establishment of the Global Programme on AIDS by the WHO, which supervised the creation of national programmes for the fight against AIDS, one can consult Cristiana Bastos, Global response to AIDS: science in emergency (Bloomington, Indiana University Press, 1999), 50-67.
guard duty" was organised\(^1\) whose epidemiological findings resulted in several articles being written and published from 1990 onward\(^2\). They specifically allowed Lazare Kaptue and Leopold Zekeng to attend international conferences, in Naples in 1987 for the Conference on AIDS in Africa and in Stockholm in June 1988 where Lazare Kaptue contributed to no less than seven presentations – clear proof of his standing in the international arena as the Cameroonian representative. In their wake, other Cameroonian academics began to work on AIDS and to participate in its political management\(^3\): the Conference on AIDS in Africa organised in Yaoundé in 1992 bore witness to Cameroon’s participation in the African and International academy on AIDS\(^4\).

This emergence coincided with the effacing of the Pasteur Centre. In 1988, its director and virologist left Cameroon at the end of their contract; their successors who were less motivated and less qualified did not assume their posts. The institution’s finances were, at the same time, affected by the economic crises which struck the Cameroon with full force; money which was earmarked for analyses and vaccinations disappeared; certain projects, such as the ambitious construction of a high security P3 laboratory, were suspended.\(^5\) In particular, the inclusion of Cameroonian in the international scene, together with their knowledge of the local politico-administrative situation furnished them with the political and scientific means to control and vie with the Pasteur Centre: in 1988 its director remembers being politely asked “not to put himself too much in the forefront”\(^6\) in the field of AIDS.

Atypical serology: beginnings of a “hot topic”

At the end of the 1980s, virologists specialising in AIDS became aware of the scientific and sanitary importance of certain anomalies discovered during the testing of blood for AIDS in Africa. Cameroon, where these anomalies were particularly frequent, took on a new status: that of an area of research requiring investment.

Although it was discreet, this research began to raise problematic aspects of the Cameroonian epidemic as early as 1985. Apart from the hardly discernable presence reported in the Cameroonian investigations, sometimes suspected of “hiding something” – a virological anomaly or a political instruction – the importance of the level of “false positives”, in other words, samples which tested positive at Elisa, and negative when retested by RIPA or Western Blot, commanded attention from the very beginning. To be more precise, some of the Western Blot tests showed “atypical profiles”: whilst certain chains were clearly located (usually capside proteins such as p24) unknown chains appeared, and other chains, although always present in infected people (protein envelopes gp41 and gp120) were not visible. This can be interpreted as the presence, in patients who were tested, of antibodies compared to a portion only of viral reference proteins, traces of a possible infection by a virus resembling HIV. From the end of 1985, this possibility was explicitly formulated because the director of the Pasteur Centre wrote to Luc Montagnier on the 24 October 1985 asking him to invite Jean-Paul Durand to his Paris laboratory so that he could be trained in the necessary

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\(^3\) Fred Eboko has analysed the politico-academic career path of these and men of science, particularly those who took over as head of the PNLS: Fred Eboko “Pourvoir, jeunesse et sida au Cameroun …” (see footnote 25).

\(^4\) Fred Eboko, “Logiques et contradictions …” (see footnote 25).

\(^5\) Guillaume Lachenal, “Le Centre Pasteur du Cameroun: trajectoire historique, stratégies et pratiques de la recherché biomédicale en cooperation…” (see footnote 10).

\(^6\) Interview with Guy Garrigue, Nîmes, 2 July 2002.
corroboration techniques “given the existence of false positives [and] the hypothesis of positive reactions with relation to similar viruses (?)”¹.

It was exactly at the end of 1985 that the problem of atypical bloods began to assume international importance. In December 1985, the prestigious journal *The Lancet* published the work of a team led by Max Essex and Phyllis Kanki, researchers at the Harvard School of Public Health, and including the Senegalese Souleymane Mboup and two French academics from Limoges and Tours, François Denis and Francis Barin, both of whom had been seconded to Dakar.² Some months earlier, Mboup, Denis and Barin had also noticed, during their early investigations amongst Senegalese sex workers, atypical Western Blot profiles. The samples were quickly taken to Harvard by Souleymane Mboup himself. The laboratory, which Francis Barin knew well having just spent time there doing post-doctoral research, was at the forefront of virological research into AIDS mainly for having isolated, in the green monkey, a virus linked to HTLV-III (the American name for HIV) the STLV-IIIagm. The elucidation of atypical bloods took on the aspect of a revelation: the Senegalese serums, tested using Western Blot made with green monkey viruses, clearly reacted to a range of simian viral proteins. The photographs of Western Blot in *The Lancet* article are crystal-clear: the Senegalese sex workers were infected with a virus which is closer to the STLVIIIagm virus than the human AIDS virus. The publication at the end of 1985 was a triple event: it provided serological “proof”, which was almost visual, of the proximity of simian and human viruses, an argument which evidently favoured the simian origin of AIDS; it placed the key to this argument in Africa – a discourse of undoubted media efficiency; but especially, it underlined the urgent problem of diagnosis as the carriers of the Senegalese virus had not been positively identified using the normal tests.

The event had rapid repercussions in Cameroon. In April 1986, *The Lancet* published a short paper co-authored by five researchers from the University of Bordeaux II and by a doctor seconded to the Service des grandes endémies de Nkongsamba (The Service for Endemic Diseases in Nkongsamba) in the south west of the country where OCEAC had been carrying out investigations since November 1985.³ This publication mentioned the presence of a “virus similar but not identical to LAV/HTLVI in Cameroon”⁴. The study simply reported the presence of positive serums in Elisa with atypical results in Western Blot, comparable to those obtained in Senegal. The investigation and its findings suggest the pertinence of Cameroonian territory for research into new colonies of the retrovirus by explicitly stressing the serological reasoning of Barin’s team (the article is quoted).

At almost the same time, Jean-Paul Durand confirmed, in the annual report of the Pasteur Centre, “the importance of the number of false positives in ELAVIA and Western Blot [which] suggest the movement of one or several other similar viruses which are perhaps transmitted in the same way”. During the following two years, the Virology Service of the Pasteur Centre attempted to set up viral cultures using “false positives” lymphocytes. If viral isolation for some patients succeeded and was sent to the Pasteur Institute in Paris, it failed in

¹ Letter 2884/85/CP/DIR, Carton Réseau, Archives of the Pasteur Centre of Cameroon, Yaoundé.
the precise case of false positives.\textsuperscript{1} The existence in Cameroon of retroviruses close to HIV remained, between 1985 and 1988, a somewhat monotonous hypothesis for concluding reports and publications: neither the Pasteur Centre nor OCEAC, neither the Cameroonian at CHU nor the transitory researchers managed to resolve the question of the atypical Cameroonian serums. In 1987 Jean-Paul Durand drew up a list of his attempts, just before finally leaving Cameroon for Dakar:

\begin{quote}
The [...] work did not allow us to suggest a solution to the problem of false positives in Elisa which provided antibodies that were isolated by Western Blot. Only intensive production of cultures in diverse and unexplained clinical tables could perhaps result in the eventual isolation of other retroviruses.\textsuperscript{2}
\end{quote}

Durand’s conclusion has the value of a paradigm: the atypical serums pose a “problem” of diagnosis, therefore one of public health, which require that we show an interest in them; the diagnostic anomalies, for their part, could provide, if they are present in affected patients, these “unexplained clinical tables” which could allow for the isolation of the undetected virus.

This two-fold relevance of the diagnostic question – the end and the means of identification of new viruses – made the fortune, in the true sense of the word, of the Pasteur Institute in Paris. From the samples sent from Lisbon, of a patient, who came from Guinea Bissau, suffering from AIDS, and who tested negative on all the blood tests\textsuperscript{3}, Luc Montagnier’s team, working in collaboration with researchers from the CNRS (National Centre for Scientific Research), succeed in isolating and in sequencing a new retrovirus which was given the name LAV-2, which became HIV-2 in May 1986. This time, the Pasteur Institute benefited from intellectual copyright, exclusive this time, of the blood tests for HIV-2 and these were marketed from 1987. Whilst the controversy surrounding the “paternity” of the first virus isolated in 1983 and henceforth known as LAV-1/HIV-1 was at its height, the Pasteur Institute held the upper hand in the negotiations which ensued: the time had come to update the available diagnostic tests with the HIV-2 antigens which the Pasteur Institute had patented.

The importance of such a discovery, in terms of scientific visibility as much as in terms of economic value, had been demonstrated, if this was necessary, to all the researchers and institutions in the field. However, in contrast to West Africa where it was rapidly shown that the “atypical” virus which had infected some sex workers corresponded to HIV-2 which was endemic in the region, the discovery of HIV-2 did not solve the problem of atypical serums found in Cameroon and more generally in Central Africa: the reaction of “falsely positive” serums was very weak compared to the Western Blots which were specific to HIV-2.

This problem come to a head in Belgium, when a team of researchers from the Institut de médecine tropicale (Institute of Tropical Medicine) of Antwerp received, during 1987, samples from a Cameroonian couple living in Belgium. These two patients, who had developed clinical signs of AIDS, presented atypical Western Blot profiles, whether HIV-1 or HIV-2 (with very weak reaction to glycoprotein gp 120). The researchers worked at creating a culture and then did molecular analyses of the virus which had infected the Cameroonian couple, in close cooperation with a small, neighbouring firm which specialised in diagnostic

\textsuperscript{1} Which represent almost 70% of positive serums in ELISA and which possess antibodies against different viral proteins, but not against the envelop’s protein.. During the 85-88 period, 14.089 tested serums, 698 positive, 226 confirmed by WB (Paul Ghipponi, Rapport annuel sur le fonctionnement technique du Centre Pasteur du Cameroun, 1988-1989, 96. Archives of the Centre Pasteur of Cameroun).
\textsuperscript{3} Grmek, Histoire du sida, 146
tools, Innogenetics. On the 9 June 1988, Innogenetics filed a patent with the European Patent Office for future diagnostic and vaccine applications of a new retrovirus: “HIV-3”\(^1\) (1). At the Stockholm conference, the team announced, according to serological criteria, the use of a new retrovirus, different from HIV-1 and HIV-2 on the Cameroonian couple and which was called ANT-70.\(^2\)

At the beginning of 1989 a major study on the problems of atypical serums in Central Africa was published in *AIDS*.\(^3\) The results which were presented were drawn from OCEAC epidemiological investigations which had been carried out since 1986 in all the countries of the sub-region except for Cameroon. OCEAC, which was based in Yaoundé, had chosen as a scientific partner an institution which was also supported by the Coopération française (French Development Agency) but was situated in Franceville Gabon, the CIRMF (Franceville International Centre for Medical Research). We should note here that the institutional arrangement, which looked rather strange, reflected the suspension of collaboration – for more or less unfathomable personal reasons – between OCEAC and the Pasteur Centre, despite the fact that its technical profile is comparable to that of CIRMF. The samples taken by OCEACs epidemiologists were sent to CIRMF where a young French volunteer doctor, Éric Delaporte, took it upon himself to “technicalise”\(^4\) them; the unravelling of atypical serums benefited from the expertise of the Bichat Claude Bernard Hospital virological laboratory which admitted, situated as it is on the northern periphery of Paris, many patients who were migrants from sub-Saharan Africa – a considerable number of whom were infected with HIV-2 or who manifested unusual profiles. In the article, the researchers suggest, without really being able to draw any conclusions, that the many atypical serums are not only non-specific reactions (due, for example, to an environmental factor) but reveal the existence of an unknown virus linked to HIV. A viral isolate was even obtained from a Gabonese blood sample and then studied at the Pasteur Institute; the virus, called HIV-1 OY1 in the publication, was even patented.\(^5\)

Towards the end of the 1980s, an entire field of international research was focused on the question of atypical serums and the identification of new retroviruses. This led to competition amongst the most prestigious institutions of biomedical research (Institute of Tropical Medicine at Antwerp, the Pasteur Institute, Harvard School of Public Health) and lead to specialisation, not only amongst long-standing virologists, but also amongst much younger researchers. Practical principles of functioning appeared: the teams maintained links which were tantamount to mergers with diagnostic firms whilst all the while depending on African outposts where cooperative projects were organised. Research efforts, already rewarded by several publications, were justified not only by the urgency of interpretation and solving of the diagnostic anomalies, but also by reflections, defined as more “fundamental”, on the origin and the evolution of the HIVs. The simian viruses were thus studied simultaneously often because they occurred in the same areas: whilst HIV-2 was coupled with

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1 The name HIV-3 has never been officially recognised. The patent was filed on the 9 June 1988, European Patent Office, Nr 88109200.
4 “Technicalise” is a dedicated expression which is used to indicate the action of manipulating the blood samples so as to perform serological and molecular analyses.
the SIVs in certain monkeys\(^1\) in West Africa, an SIV was isolated in 1989 in a chimpanzee kept at CIRMF. When it was sequenced at the Pasteur Institute, it was found to be very close to the known HIV-1s\(^2\), renewing speculations on the simian origin of the AIDS pandemic.

The discoveries of CIRMF in Gabon and the publication in March 1990 of a partial analysis of the “Cameroonian” clone ANT-70\(^3\) in some ways tightened the noose around Cameroon at the exact moment when the local biomedical field was busy reorganising itself with the withdrawal of the Coopération française and the Cameroonians academics taking over. They would be the ones to play a decisive role in the identification of the Cameroonian viruses and contribute to making Cameroon a “hotbed” for virological research.

**How the territory became favourable: Isolation of hiv-1 o, 1988-1994**

The beginning of the 1990s saw the writing one of the most glorious pages in Cameroonian biomedical history, the identification of a “Cameroonian” group of viruses, HIV-1 group O; at the same time it heralded scientific and social mechanisms which would explain and maintain the retrovirological attraction of Cameroon: the establishment and increase of cooperative projects which enabled the emergence and training of young researchers, which strengthened the position of their mentors and which culminated in first class scientific discoveries. The director of the blood bank, Léopold Zekeng, who was put in charge of the CHU blood bank in 1990, gave a (voluntary) account which warrants being heard:

So, our first breakthrough, the first big feather in our cap, goes back to the discovery of what is today known as group O. At the beginning of the 1990s we admitted a young woman of 26 who showed all the signs of AIDS, [...] diarrhoea, [...] temperature … We carried out the Elisa test (…) with, unfortunately, negative results or indeterminate results.

Then […] quite by coincidence, I received a bursary from the our German collaborators to spend a month in Germany at the Lutz Gürtrler laboratory (at the Max Von Pettenkofer Institute in Munich) in order to perfect my skills in molecular biological techniques […].

So here we are, the 1st May 1990 and I spend the whole night flying to Germany and finally arrive in Munich […] I had brought with me seven problem samples taken from patients [including that of the woman patient]. Together Professor Gürtrler and I isolated the lymphocytes and placed them into cultures, strangely, it was only that of the woman that began to grow […]. We later called it MVP-5180. At the end of my training period, Lutz said to me, “As there has been viral development, I am going to create chains of Western Blot from the cellular culture for you so you can return to Cameroon to work”.

Lutz created Western Blot chains [from the proteins of the Cameroonian virus] and [checked] to see that all went smoothly. He tested them on [serums of] positive German patients, and haemophiliacs. He was greatly surprised, […] the crossed reaction was weak, especially on the envelope’s protein. The laboratory technician said “It hasn’t worked, I’ll chuck it into the bin” and [Lutz] said “No, something’s wrong: here is a sick [Cameroonian] woman who is infected, we have isolated the virus, we have tested [the virus of] the sick woman against the [serums of] haemophiliacs and there is a discrepancy. There is a strong possibility that these two viruses, even though they are responsible for AIDS, do not possess the same properties”\(^4\).

The attentive reader will have recognised in the method used, the elucidation of the “unexplained clinical table” which Jean-Paul Durand had hoped for in his time. It is indeed from a diagnostic incompatibility that the virus is detected and then characterised, and the “home made” elaboration of a Western Blot test using proteins from the Cameroonian virus,

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4 Interview with Léopold Zekeng, Yaoundé, 29 April 2002.
results in a “inverted” image: a patient who is infected with a “European” virus is not diagnosed as positive with the Cameroonian test. It is simply another type of virus.

As part of his doctoral thesis, another young Cameroonian member of the team, Jean-Marie Tsague, participated in the culture and the sequencing of the virus in Germany. The cloning and the sequencing took many long months, absolutely necessary because of the “highly divergent” nature of the clone. The importance of the work in hand did not escape the Behring laboratories. They actively supported the project and helped with the perfecting of the specific immunological tests of the MVP-5180 colony which were used at the CHU to estimate the prevalence of the Cameroonian clone.

At the same time in Antwerp, the team led by Peter Piot and Guido Van der Groen continued its investigations on the ANT-70 clone which also underwent a sequencing which covered almost the entire genome. In collaboration with Innogenetics, Elisa tests were adjusted which allowed for the detection of specific infections by the viruses related to ANT-70. It was no surprise when the Antwerp team, already joined by a few former volunteers at the CIRMF, Martine Peeters and Éric Delaporte, turned towards Cameroon for a preliminary survey concerning the movement of such viruses. Contact was established with an immunologist at the Faculty of Medicine, the head of the Central Hospital, Peter Ndumbe, who already had an impressive background in the field of international medical cooperation (he was the spokesperson for WHO in the field of vaccinations). Cameroonian serums were sent to Antwerp and two young researchers (John Nkengasong and Phillip Nyambi) were trained in Antwerp as a result of the links which had been formed, in some way parallel to the Yaoundé-Munich axis which had been established with Zekeng and Kaptue. The study on the serums sent to Antwerp was published in July 1993; it reported the presence of viruses similar to the “aberrant ANT-70 clone” from Cameroon and Gabon.1

In 1992 in Yaoundé and in 1993 in Marrakech, the two teams, now in competition with each other, met one another as well as specialists in the field. Taking cognisance of the great similarity between their two viral clones, they coordinated the publication of their results accompanied by a phylogenetic analysis of the sequences which had been obtained. The March 1994 issue of the Journal of Virology contained an article signed by Lutz Gürtler, four other German authors and three Cameroonians, Zekeng, Tsague and Kaptue, and, in the following pages, an article by the Belgian/Netherlands group from Antwerp where none of the Cameroonian authors of 1993 appeared. The German/ Cameroonian article combined the results of the two articles and suggested that the MVP-5180 clone and the ANT-70 clone be grouped together in a new “sub-type”2 of HIV-1, “sub-type O” (for outlier).3 The two articles both stressed the importance of this point in order to question the “natural origin of HIV-1” the O variant filling the “very special” place of “the closest relation to HIV’s ancestor”, probably embodying “a common origin for human and chimpanzee lentiviruses”.4

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2 This terminology (the HIV-1 viruses organised into “sub-types” including the “sub-type O”) turned out to be very provisory.
4 Vanden Haesevelde et al. “Genomic cloning …” (see footnote 53).
The phylogenetic importance of this new variant was confirmed at the end of the summer of 1994 in *Virology*¹: Montagnier’s team at the Pasteur Institute of Paris published the sequence of a virus similar to the two Cameroonian clones which had been isolated in 1992 from a European patient who had no apparent link with Africa. Faced with the differences which existed between the two apparently similar clones as well as their geographic deployment, the article suggests consolidating them into a single “group” O (for *outgroup*), different from an M “group” (major group) where all the other “sub-types” of HIV-1 are classed. In order to be sufficiently technical in its details, this reorganisation of nomenclature of HIV-1 clearly designates Cameroon as the “birthplace of HIV-1”² where new clones of the human viruses needed to be sought:

The discovery of a virus like ANT-70 (……) will perhaps lead us to the origin of the HIV-1 family. The analysis of additional SIVcpz and other different human clones could well provide us with the information necessary for attaining this goal.³

But more than the evolutionary considerations, it was clearly the question of the diagnosis of the “O group viruses” and their epidemic emergence which was the burning issue. From June 1994, researchers in the virology laboratory at the Claude Bernard Hospital (which was associated with INSERM) presented a preliminary evaluation of the sensitiveness of the commercial tests for the detection of infections of the group O virus. The title of the article published in *The Lancet* and which was relayed throughout France by *Le Monde⁴* was unequivocal: “Séronégativité HIV-1 and HIV-2 des patients infectés par le HIV-1 sous-type O”⁵ (“HIV-1 and HIV-2 seronegativity in patients infected with the HIV-1 sub-type O”). The study coordinated by François Simon, a para-cytology doctor who had already participated in the Gabonese atypical serum study, tested and compared the findings of the main screening tests of samples from about a dozen patients who had been monitored since 1990 at the Bichat Hospital, as well as in a few French hospitals and who had shown atypical reactions to Western Blot in spite of signs (clinical or biological) of being infected with HIV. After having proved, using “home made” tests perfected with Behring, that these Cameroonian and French patients were carriers of HIV-1 O, the French authors confirmed the dissemination in Europe of O variants, a highly disturbing fact given that some of the identification tests in common usage had systematically come up negative with these patients. The International AIDS Conference in Yokohama on 8 August 1994 devoted a “Special Recent Report Session” to infections of the O group thereby ensuring media coverage for its discovery and the fears that it was beginning to raise. At the end of 1994, researchers at the Centers for Disease Control in Atlanta went one better in *The Lancet* about the lack of sensitiveness of the tests available in the United States for HIV-1 O which had been assessed with serums taken in Yaoundé by Zekeng and Kaptue. Together they warned “that the adaptation of current tests is urgently needed”.⁶

³ Vanden Haesevelde et al. “Genomic cloning …” (see footnote 53).
The stakes were not only health related: the Antwerp, Munich and Pasteur Institute\(^1\) HIV-1 O clones had all been immediately patented and Innogenetics, who benefited from the precedence, marketed a specific test for group O at the end of 1994. There is no need to insist on Cameroon’s attraction: it was considered as the “home” of the virus. The 1994 series of publications mark, in a way, the official beginning of a veritable race for blood samples. Contributors to *The Lancet* expressed this in terms that were totally unambiguous:

> Another challenge for public health […] An intense hunt has already begun to collect other isolates of the O sub-type (so that the immunological tests can be evaluated and modified) and other variants of HIV. A sudden lively interest is evident for what was formerly simply a laboratory brain teaser. […] The quest began in Central Africa […] Let us hope that the effort to detect and describe the HIV variants will be more coordinated than the unbelievable scramble for HIV-2 which, in 1985, saw research teams, institutions of public health and industry squabble over opportunities to collect blood samples and the specimens themselves.\(^2\)

### The race for serums (1994-1998)

The 1994-1998 period was one of scientific affirmation for Cameroon which established itself as a territory of interest through the series of publications during 1994. More then seventy articles, in international journals dealing with the subject, would be published by Cameroonian or foreign academics, compared to a dozen or so during the 1989-1993 period. This unquestionable visibility reflected an intense activity and a clear increase in the players in Yaoundé, particularly, as we have seen, at the beginning of the 1990s.

The race for Cameroonian blood samples had a double goal: the identification of new clones of the virus and a quantitative supplying of serums. The isolation of viral variants (from lymphocytes from infected patients) had proved, in the case of HIV-2 and HIV-1 O, its economic and symbolic value but also its extreme difficulty: for example, seven years were to go by between the initial detection of the ANT-70 clone and its definitive identification. This “noble” objective co-existed with a more subdued but perhaps more practically important organisation, the collection and stockpiling of serums from patients infected with the variant viruses. These serums which carried the “immunological trace” of a patient’s infections were needed to assess the sensitivity of the tests and their (re)adjustment or were used as reference during research into atypical infections. In contrast to the viruses which could be cultivated *in vitro* and whose protein components could be produced by genetic engineering, the serums constituted a unique biological material which was limited in quantity. The serums and the “serum banks” assumed, in the strictest sense of the word, an economic value. A researcher in the field remembers the first few months after the discovery of HIV-2 as a period when “in certain Parisian laboratories, a millilitre of HIV-2 serum was sold for a fortune”.\(^3\) In 1994 the diagnostic problems posed by HIV-1 O caused Cameroon to be coveted as a source of serums and lymphocytes. To say that the fight in Yaoundé was grim would not be an exaggeration:

> When one found someone with group O he was bled like a pig so that the blood could be sold. I saw this many times. Pockets. We emptied their pockets. The guy who was about to kick the bucket, we rifled his pockets and sold the contents. It was all sent away. It was the Americans who first suggested this golden bridge for this type of activity.\(^4\)

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\(^1\) The patents concern the peptic sequencing which could be used for blood testing and nucleic sequences of PCR beginnings, which are useful in so-called “molecular” identification and especially for research itself (detection and sequencing of new clones).


\(^3\) Interview with a French doctor, 2003.

\(^4\) Interview with a French doctor who had been a development worker in Cameroon, 2002.
Lazare Kapute and Léopold Zekeng, the two Cameroonians involved in the discovery of group O, obviously benefited from the passing fancy for the Cameroonian serum because of their triple status, newly recognised scientific experts, directors of hospitals and local notables, a trump card when it came to negotiating the setting up or carrying out of research. The Munich-Yaoundé collaboration was continued particularly as regards the assessment of the diagnostic tests. The two academics began to increase official collaborations with the North: their list of publications revealed the fact that they had (occasionally) established links with other partners, such as the Abbot (Chicago) or Organon (Netherlands) companies and the University of Kyoto in Japan. Their work was not limited to virological analyses of the O variants; questions of public health, methods of prevention and the epidemiology of the HTLVs, the other family of retroviruses found in Cameroon were also part of the areas of expertise of the CHU researchers. The projects put in place foresaw the need for and supported the training of young researchers “in the North” such as Jean Marie Tsague or Innocent Mboudjeka (in Kyoto) to whom the most technical aspects of the work were entrusted.

The collaboration between the Institute of Tropical Medicine in Antwerp and its local representative, Peter Ndumbe, continued and went hand in hand with the brilliant international careers of Phillip Nyambi and John Nkengasong, both of whom were trained in Antwerp and head-hunted by American institutions. Peter Ndumbe also proved to be a person who could not be ignored on the local scene by organising around himself a “radial” group of diversified collaboration which extended from organising the production of Cameroonian diagnostic test (a project in collaboration with Canadians) to the molecular epidemiology of Hepatitis C.

One of the former members of the Antwerp group, Éric Delaporte, would contribute, by becoming interested in the Cameroonian virus, to the emergence of another Cameroonian

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figure in the field of research into AIDS. In fact, in 1994 Éric Delaporte was appointed head of the research laboratory into the retroviruses ORSTOM (which later became the IRD), the French public establishment charged with research abroad. Based in Montpellier, having already set up collaborative ventures in Dakar, Éric Delaporte was planning to install his team in the inevitable town of Yaoundé. With the main sites in the town (the CHU, the Central Hospital and the Faculty of Medicine) already “occupied”, he turned to the man who was the director of the PNLS in 1995, Eitel Mpudi Ngole, an army doctor and specialist dermatologist and venerologist who had trained at the École de santé navale in Bordeaux. Set up in the heart of a military hospital, this collaboration consisted of the biological and clinical follow-up and therapeutic treatment of a multitude of sick people. The virological analyses of the samples and all the molecular tests were done in Montpellier. A link between Montpellier and the Military Hospital was thus established in 1995 and Colonel Eitel Mpudi Ngole become an international figure. He knew how to exploit this position by becoming, in turn, an important personage on the local research scene.

The Pasteur Centre became rapidly involved in virological research into AIDS – a field described as a “cat and dog battleground” – even foreseeing the announcements of 1994. Through the impetus of Phillipe Mauclère, the military doctor who had been appointed section head in 1992, the virology laboratory prepared itself for a large scale study for the detection and analysis of “atypical serums”. The Pasteur Centre’s first major trump card was to organise a massive programme to obtain serums, especially atypical serums, through a hospital network which it was able to establish because it was the PNLS’s official centre for the verification of serums and coordinator of other research (polio and HTLV). In addition to its daily clients at the HIV screening centre, the Pasteur Centre therefore had access to a considerable amount of blood samples in 1993.

In an economic context which remained difficult, Phillipe Mauclère also benefited from a “deal” with the Sanofi Diagnostics Pasteur laboratories and their Research and Development service. At no charge, they provided the material for rapid identification (tests of the Elisa type) for HIV and HTLV serologies and in exchange the Pasteur Centre would provide Cameroonian serums, in other words, isolated viral clones. From as early as 1990 it would appear, the firm’s knowledgeable experts rekindled interest in Cameroonian HIV and the agreed investment (in the order of 25000 tests) is without doubt indicative of the hope placed in the Cameroonian serums. These same experts, aware of the work in progress on the O group in Antwerp, Munich, Paris and Yaoundé, advised and even supervised, in January and then in April 1994, the first retrospective work of the laboratory’s blood bank in an attempt to find samples which were carriers of an infection by the (sub-type) group O which were absolutely necessary if the firm’s tests were to be adapted. Phillipe Mauclère remembers:

> It was the people from Sanofi Diagnostic Pasteur who contacted me and said: “There are variants in circulation and it will be interesting to work on them and we have the necessary tests to detect them”. […] This was even before the paper on group O came out […] and we started to work on a blood bank. We simultaneously used the commercial test and their makeshift test: [on certain serums] the

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1. The acronym ORSTOM initially stood for “Office de la recherche scientifique et technique outremer” (Overseas Office for Scientific and Technical Research) before becoming known as “Orstom – Institut français de recherche scientifique pour le développement en coopération” (French Institute for Scientific research for Cooperative Development) and later “Institut de recherches pour le développement (IRD)” (Research Institute for Development).
3. Sanofi Diagnostics Pasteur took over the diagnostic activities of Pasteur Productions.
commercial test was negative and their test was positive for the O groups. That was the beginning of the research [...] [but] they were businessmen and interested in the development of a test and I soon began to look for scientific partners.¹

Phillipe Mauclère found just the partner that he was looking for in François Simon whom he met in December 1994 through Sanofi in Paris.² His experience in the identification of HIV viruses was used to advantage.³ Since 1993, Phillipe Mauclère had perfected and applied a new protocol for serological identification at the Pasteur Centre which was faster and cheaper, by replacing Western Blot confirmations with a series of Elisa tests: together they adapted this algorithm for the rapid detection of O variants. The technicians Tina Abada and Jermic Mfoupouendoum, already experienced in the rapid identification of HIV serologies, could henceforth screen the overcrowded blood banks in search of HIV-1 O (+) without having recourse to Western Blot or to genotyping by using biological molecular techniques. The results were spectacular.

By the end of 1995, sixty-nine patients who were infected with HIV-1 O were identified using the Pasteur Centre serological protocol. Lymphocytes were sent to Françoise Barré-Sinoussi in Paris for her to try to isolate and sequence the new specimens. Another technical innovation proved itself to be invaluable for the detection of the “O groups”: Francis Barrin, from the Centre hospitalier universitaire (CHU) in Tours, perfected and validated, on the Pasteur Centre serums, a serological technique (a variation of the Elisa test, using synthetic peptides) which allowed for the efficient identification of the HIV-1 group⁴. The technique called GSEIA would be routinely used at the Pasteur Centre from 1996 for the retrospective study of its blood bank since 1986 and resulted in the identification of an additional series of serums infected by HIV-1 O. International publications did not immediately explain these technical innovations and the intense work being carried out by the Pasteur Centre “crisis team” as Phillipe Mauclère like to call them. The results of the HTLV, the initial priority in terms of research, accounted for the totality of this research up until 1997,⁵ before the vast quantity of epidemiological work on the O group began to appear in journals.⁶ Pasteur’s epidemiological data confirmed first impressions particularly that of Zekeng’s team:⁷ the prevalence of HIV-1 O, even in Cameroon, remained feeble – therefore, no “emergent virus” on the horizon.

¹ Interview with Phillipe Mauclère, Paris, 3 July 2002.
² IX Symposium on Retroviruses held at the Nikko Hotel on 2 December 1994 in Paris.
³ François Simon also benefited from being funded by the ANRP specifically for HIV-1 O infections.
⁵ The work on HTLV benefited from several field studies from the Centre Pasteur du Cameroun with important results. For example: A. Gessain, P. Mauclere, A. Froment, M. Biglione, J. Y. Le Hesran, F. Tekaia, J. Millan, “Isolation and molecular characterization of a human T-cell lymphotropic virus type II (HTLV-II), subtype B, from a healthy Pygmy living in a remote area of Cameroon: an ancient origin for HTLV-II in Africa,” *Proceedings of the National Academy of Sciences of the USA*, 92 (1995), 4041-4045.
HIV-1 n and the quest for the “missing link” (1998-2000)

But the interest in Cameroon had already been rekindled when these somewhat “disappointing” results appeared. Since 1995 the report of the Pasteur Centre’s activity had mentioned the existence of serums which remained indeterminate, that is to say which did not belong to either group O or to group M of the HIV-1. One of them concerned a woman patient of forty who, in May 1995, showed a typical clinical picture of AIDS and who died in December. Her blood count was indeterminate: certain Elisa tests (in competition) were negative, others positive whilst she showed a normally positive Western Blot HIV-1 profile. One could say that she would have passed unnoticed (negative or positive according to the ELISA test applied) with a classical identification protocol. The GSEIA tests “specific to the group” were negative for the M and O peptides. On the other hand, the serum showed a marked reaction when a test conceived by Innogenetics was used with peptides of an SIV taken from a chimpanzee from Gabon. The importance of such an atypical infection escaped no one and the lymphocytes sent to Paris resulted in a viral isolation.

Retrovirolological war was declared in Paris between the Pasteur Institute of Paris, the Cochin Institute and the Bichat-Claude Bernard Hospital who all took up cudgels: by the end of 1996 the complete sequence of this new clone called YBF-30 was registered and phylogenetic analyses had begun at the Pasteur Institute. An application for patent which included the methods of sequencing (based exclusively on the PCR methods) was filed on 6 December 1996. The Pasteur Centre then adapted the GSEIA technique used to detect clones similar to YBF-30, so as to estimate their prevalence: there were few cases and only five cases were confirmed as a result of the study of serums which had been stockpiled between 1989 and 1998. These sporadic cases were however enough for the Paris-Yaoundé collaboration to retain exclusivity of a problem of major scientific interest.

It was in September 1998 that the prestigious journal Nature Medicine announced the discovery of a new HIV-1 virus which was distinct from the M and O group and which was signed, amongst others, by François Simon and Phillipe Mauclère. The presence of a few cases discovered in Cameroon allowed for the creation of a new group, the group N which stood for Non-M and Non-O or for New. In contrast to the case of the O group four years previously, diagnostic problems posed by the clone were fewer not only because it seemed to be extremely rare, but rather because the majority of the tests came out positive. It was its genetic originality which was particularly highlighted by the authors: the YBF-30 virus is closer to the Gabonese SIVcpz than to the two groups of human HIV-1, a phylogenetic position which, for the first time, affirmed a direct transmission of the ancestor of the virus from chimpanzee to humans. The article substantiated and reaffirmed the importance of Cameroonian territory by opening up obvious perspectives: the possibility of chimpanzee SIV being closer to the two different HIV-1, research into the “lentivirus close to the M group or to the O group in non-human primates is of capital importance” and Cameroon, indisputably “at the heart of events pertaining to inter-specific transmission”, is the origin – supposed – of the AIDS epidemic. Formulated by Pasteurians according to the doubtful register of the

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3 Patent (France) Nr FR19960015087.
5 For certain parts of the genome only.
evolution of man in the “Out of Africa” mode, it is this quest for the “missing link”\(^1\) that is being launched in Cameroon.

A “broad study amongst non-human primates” such as the article mentions is, in effect, underway: since 1997 the Pasteur Centre has been working, coordinated by virologists at the Pasteur Institute in Paris, on simian retroviruses by taking blood samples from monkeys in the zoos in Limbe and Yaoundé. Since 1997 as well, the IRD has put a lot of effort into this issue, by launching a vast investigation into the spread of SIV amongst the monkeys eaten as “wild meat”, sold in markets or kept as pets. Backed by its veterinarian, Xavier Pourrut, who arrived from Dakar, the IRD team made the most of experience gained both in the field and in the laboratory when, in the preceding years, it had run a similar project in Senegal. Lazare Kaptue also took blood samples from the monkeys in the Yaoundé zoo for his Japanese partners. A competition sprung up *in situ* for blood samples and in the “North” for the isolating and identification of the viruses, which was even fiercer than the one concerning human variants.\(^2\) From 1999, publications began to appear. The Pasteurian team obtained two clones of SIV from chimpanzees which were even closer to HIV-1 N.\(^3\) Beatrice Hahn an international leading light in virology, could henceforth state that the problem of the “origin of HIV-1 has been solved”.\(^4\) An entire series of new SIVs analysed in Europe, Japan and the United States were identified in different species of Cameroonian monkeys: the problem of the origin having been solved – according to Beatrice Hahn – a new scientific discourse asserted itself and was mainly transmitted in publications that were co-signed by the IRD.\(^5\)

Prompted by current fears concerning the “emergent viruses”, these discourses warned against the risk posed by the consumption of “wild meat” which could expose humankind to the emergence of an HIV-3 or an HIV-4 – a problematic message which requires further analysis.

**Epilogue and conclusions**

At the beginning of this new millennium, the Cameroonian territory is arousing a passion whose acuteness and topicality cannot be denied. Remarkable institutional configurations have appeared, an indication of the intensification of the “research in partnership and on a specific subject”\(^6\) which has imposed itself as the principal method of scientific work in Cameroon. Let us take two recent examples: at the very end of the 1990s Dr Mpudi-Ngole added two additional projects to his “historic” collaboration with the IRD, one with the CDC in Atlanta and the other with John Hopkins University (Baltimore) whose most obvious tasks are the collection and subsequent dispatching of blood samples across the Atlantic. Although they are strictly independent of one another on a scientific level\(^7\) the three projects share the same building in the city centre and, it is often said, the same freezers – an extreme picture of

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2. Guillaume Lachenal, “Le Centre Pasteur du Cameroun …” (see footnote 10).
6. To be understood in the strict sense of the word: a device for short term financing (a few years) by an “agency with means” functioning by tender (the NIH is an historic example as is the ANRS in France) and explicitly controlling the “North-South” scientific relations.
7. To this day (October 2004), the three parties have not signed any joint publication.
the “juxtaposition “ of the North-South segments which underlie Cameroonian research. In the same vein, the destiny of “l’Hygiène mobile” a modest building on health hill, is just as evocative. From 1998 Dr Zekeng has installed an identification centre in a disused ward inherited from the colonial Health Services, for the study of microbicides. These premises, repainted in the interim, house the freezers used to store the massive consignments of blood samples which will be sent to the American Food and Drug Administration and to the IRD in Montpellier. In a nutshell, this is the intriguing story and picture of the minimalist institutional conditions where the public research of an economically strapped State is cobbled together, often with great inventiveness.

I wanted this story to be an illustration: Africa has not waited for the appearance of tritherapies, the relative lull in western epidemics, and the controversy surrounding the general availability of generic treatment in order to be at the centre of a veritable scientific and medical turmoil. By giving this account the urgent rhythm of the “race for serums” I wanted, by the very form of the narrative, to attempt to show the inevitable integration of an “African periphery” into large scale international science. It goes without saying that my account will raise a series of comments and complementary analyses. The sociology of the actors and the different forms of their global circulation warrant an in depth study in order to describe better the appearance and reconfiguration of a transnational field. A study of institutional modalities and technologies of work in local research which would compare the strategies of sample collection and of funding would also permit the evaluation of the novelty – and equity – of the scientific practices which have been established. Certain controversies concerning Cameroon, specifically those about the origin of HIV, need to be scientifically analysed. Finally, the “answers” which the “race for serums” has presented, its public representations, indeed its “subjects’” reactions are just so many possible anthropological view-points to this story.

For we must remember that the Cameroonian race for serums, in spite of many brilliant success stories, has been disturbing – not so much because of its logic but for the impropriety of “individual and collective hostilities […] interminable and ludicrous” which brought the majority of the players into conflict in a dramatic epidemiological context. However it is, not without paradox, from the very strategies of scientific capitalisation that the most desirable aspects of the “scientific race” have emerged: the interventions by public health gradually became indispensable to the recognition of the projects before access to anti-retrovirals in Africa presented itself as an “urgent scientific question” which, seen in this light; was capitalisable. This did not announce the discovery of any “new clone” but recommended the funding and distribution of a generic tritherapy, Triomune.

1 In collaboration with the NGO Family Health International.
3 To the point that they resulted in audits and meetings which were explicitly aimedat “restoring order”.
4 These words are those of Céline describing the colonial society of Douala: Louis-Ferdinand Céline, Voyage au bout de la nuit (Paris, Denoël, 1932, rééd. Gallimard, 1952, 125).
Law, Ethics and AIDS in Sub-Saharan Africa
Senegal as a Case Study

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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.

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 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 article 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 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 Judicial 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 Committee for Research into AIDS 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 is 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 an ethic in a situation 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 ill 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 dominated by the AIDS epidemic. This epidemic is one of the major challenges of

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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. 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 AIDS 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 Nation development agencies (UNDP, WHO, UNESCO, UNAIDS) in America (USAID, FHI) or those of England. Canada also plays an important role, with the HIV/AIDS legal network “Aidslaw” 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 recherche dans les pays en développement”. In March 2004 the “Premières journées

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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>
francophones d’ethique 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 “Network 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 rare.

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.

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

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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.

inaction, not to say denial of the reality of the epidemic, are known.\textsuperscript{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 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.\textsuperscript{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 text\textsuperscript{3} 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.\textsuperscript{4}


\textsuperscript{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 \textit{Journal Officiel de la République du Sénégal}.

\textsuperscript{4} Conseil national de lutte contre le sida, \textit{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 inter-nation 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 Declaration” whose ten basic principles remain extremely relevant. It was followed by

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1 Réseau africain de recherche sur le sida, 1993, 2.
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 lead 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 rights of man 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 researches
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 for 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.

> 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

debating HIV/AIDS religion” where ethical questions were raised. Recently the fraternity of doctors 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. This work consists of a manual on the ethical and legal questions posed by the acceptance of responsibility for orphans and vulnerable children (5. Inclusion sociale). Synergy for children has opened a voluntary and anonymous screening centre in Pikine-Guédiawaye where the child will be accompanied and where an “Ethic” cell 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 practicing 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” 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. 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 research on confidentiality as well as other less specific thesis. However, these works are rare. Information relating to

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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’odontostomatologie, 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 Jurisaida, 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 forum, 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 Research into Health (CNRS) and its 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, 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

committee since 1955\textsuperscript{1} 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 directors 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 was, if they were mentioned at all. Reference to basic laws recognised at international level (Helsinki, Manila, AMI) 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 submitted by renowned research teams or institutions from the North they generally contained

\textsuperscript{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.
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 manual published in 2001 by La Recherche. 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 Senegal 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.

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

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

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)

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A Oral History of HIV/AIDS in the Congo

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The first cases of AIDS in the Congo

The first cases of AIDS in the Congo (known at that time as Zaire) were diagnosed in October 1983 in Kinshasa by an American-Belgian team working in close collaboration with Congolese doctors. This joint diagnostic work was inspired by the discovery, the preceding year in Belgium, of cases of AIDS in patients from Central Africa amongst whom some were Congolese.¹

Let us recall that it was in 1981 that the first diagnoses of AIDS was made in the United States. Naturally, the date of occurrence of the illness was earlier in both the United States and Africa. This was described by Ngandu Kabeya the Congolese Minister of Health in 1987:

When one looks at the files and goes back in time one discovers several cases of patients who, in the past, have shown grave signs of AIDS. Today it is possible to state that these patients died of AIDS. In 1977, 1978, 1979 and 1980 some cases were already known but they were isolated. Patients arrived either with persistent diarrhoea, pulmonary problems, high fever, weight loss etc and all of these symptoms lead to death without us being able to arrive at a diagnosis.²

This statement correlates with evidence gathered at the time. Bilonda Lwamba recalls a cousin who died in 1979 of an inexplicable disease whose symptoms resembled those of AIDS:

Just before his illness began, his wife – his cousin’s wife – had been sent back to her village (district of Kongolo in Katanga) because of infidelity [adultery]. But when the husband fell ill, the in-laws thought it best to send the wife back to Kinshasa so that she could be at her husband’s sickbed. He died in 1979. Some time after his death, the wife returned home to live in the town of Kongolo. There she died, two years later. In Kongolo, this woman had not been chaste. She had sexual relations with other men in spite of the custom which demands that a widow practises abstinence for at least one year. Her lovers died several years later of the same disease but as far as they were concerned, we knew that it was from AIDS.³

This account shows that the AIDS virus was present in Kinshasa before 1979. Similar deaths had been recorded in 1977. We could mention the case of Jean-Pierre, a young man of about 20, whose story was told by Tsasa Umba:

¹ Comité national de lutte contre le sida (CNLS), Réponses à vos questions (Editions Saint-Paul, Kinshasa 1988), 18.
² Ibid.
³ Lwamba Bilonda, lecturer in history at the University of Lubumbashi, interviewed in Lubumbashi on 15 April 2003 (in French).
Jean-Pierre was a contemporary of mine. We lived in the same street, rue de la Source, in the village of Lemba. He was a musician. His mother, Mummy Maria, was a great friend of my godmother. He died in 1977 after developing tuberculosis. He was only admitted to the Makala Sanatorium after his illness worsened.

What made Umba think that Jean-Pierre had died of AIDS was the fact that, even though he was sick at home for a long time before going to hospital, no one in his family developed tuberculosis. He added that, during the last months before his death, he showed symptoms which are today seen in victims of AIDS who are in the final stages of the disease: tuberculosis together with intense diarrhoea especially after eating; loss of hair; marked weight loss. In this regard he offered the following information:

At that time, the following event caused panic amongst young people: tuberculosis seemed to resurface in Kinshasa. Many cases were reported amongst young people, especially movie stars.

An extreme case is that of César Ntoto all of whose wives died of AIDS. He himself succumbed to the same disease in 1993. A remarkable fact is that his first wife died in 1975 of the same disease as that of the different women who succeeded her as spouses.

It was also in 1975 that Marc Nkongo, residing in Kilangwe Avenue, Kinshasa-Lemma, died of a disease that the doctors were unable to cure, reports Emmanuel Phuati Ndele. “Had he have died today”, he adds, “he would have been labelled as having AIDS. The young woman that he had married three years previously, in his third marriage, died two years later, in the same circumstances.”

Similar cases were noted not only in Kinshasa during this period. Mr Tshamala, an employee of the SNCC in Lubumbashi, mentioned the case of a student at the University of Lubumbashi who lived in the same students’ residence as him:

In 1980 our neighbour died. [...] We lived in Camp Luano [the students’ residence]. Like me, he was a married student. He came from Bas Congo. He had registered as a student only two years earlier. He was an employee of Air Zaire but had asked for absence of leave so that he could study. His death disturbed many people for we feared witchcraft. The Bakongo, people of his tribe, are often accused of using witchcraft. This student had hardly come to any lectures. He was often ill, for months on end. He was admitted several times to the Lubumbashi University clinic. The last time that he was admitted, he had developed the same symptoms that are seen in sufferers of AIDS who are in the final stages of the disease. He had lost so much weight because of his constant diarrhoea that it was said, a few days before he died, that he weighed no more than twenty-eight kilograms. It was said that his parents reproached him for only paying attention to his wife although she was sterile. It was planned to transfer him to Kinshasa where he would receive better care, but he died just as plans were coming together. Still, his mortal remains were returned to Lower Congo.

Doctor Léopold Malonda indicated that during 1982-1983 he treated cases similar to those mentioned above in the Mont Amba University Clinics in Kinshasa. These patients came from Boma and Matadi in Lower Congo.
AIDS, a foreign disease

Congolese opinion is convinced that HIV/AIDS, at least in its present form, is of foreign origin. The reason for this is that the first cases of AIDS, confirmed or suspected, were affected people who had regular contact with foreigners. In Kinshasa, a group of prostitutes known as the “Londoners” were amongst the first people to contract AIDS. Testimonies such as that of Mr Kilo mention the death of the “Londoners” who practised their profession in the seventies.

Nzali died a long time ago. She died because she was a Londoner. She was a beautiful girl who loved only white men. In fact, all the Londoners in our area died of AIDS. [There follows a list of twenty names.] All the men who associated with them are dead also.  

Franco Makiadi Lwambo, a well known popular Congolese musician who was known to draw his inspiration from news items and current affairs also referred to prostitutes in his well known song Attention na Sida:

Hey! Good gentlemen! Hey! Citizens! Beware of the prostitutes! And you, good ladies! Citizens as well, make sure that your men folk use condoms.

Let us remember that at that time, in keeping with the doctrine of authenticity, the Congolese were called “citizens” in order to distinguish them from “gentlemen”, in other words, foreigners.

The conviction that AIDS was of foreign origin was upheld by well informed people of repute like Professor Zirimwabagabo Lurhuma who stated in the magazine Jeune Afrique that AIDS was brought into Lubumbashi by an HIV positive Pakistani who infected several prostitutes during a stay in the town.  

In the interview mentioned above, Tsasa Umba alludes to the stars who were also the target of popular accusations because of their relationships with foreigners. In 1974, for example, during the Ali/Foreman boxing match rumour had it that the woman star Abeti Masikini had sexual relations with George Forman’s two dogs. Even if this rumour was groundless, it is true that Abeti Masikini kept company with the Americans and other foreigners who had come to cover the event. She died of AIDS some years later. Congolese opinion dates the appearance of AIDS to the period when the luxury hotels which accommodated foreign delegations – the Intercontinental, the Memling, the Okapi – attracted visits from Congolese prostitutes.

The Congolese bourgeoisie was also in contact with foreigners. Their financial means allowed them to leave the country and to associate with foreigners. The most famous case is that of Niwa Mobutu, the eldest son of President Mobutu, who died of AIDS during the eighties. Kabeya Ngandu, a doctor and Minister of Public Health said nothing more or less when he made a public statement referring to

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1 In Kinshasa this name is given to prostitutes who practice their profession in foreign circles, particularly amongst whites. The “Londoners” are to be found on the Boulevard 30 June, particularly at night. There, tourists and other foreign visitors, pick them up. They also frequent well known hotels, discotheques, restaurants and popular night clubs.

2 Mr Kilo, resident at 9 rue de la source, Kinshasa B Lembia, interviewed on 30 January 2003 in Kinshasha (in Lingala).

3 Jeune Afrique, 1355-1356 (December 1986), 4. The same year, with the help of Daniel Zagury, a Parisian immunologist, Lurhuma began to experiment with a vaccine against AIDS, MM1, which turned out to be a false hope. See Mirko K. Grmek, Histoire du sida: Début et origine d’une pandémie actuelle (3e éd., Paris, Payot, 1989), 286. See also, in this volume, Paul Kocheleff’s paper.

4 Several years later, Franco Lwambo Makiadi sang Na bala nangai ibwa which is Lingala for “I would prefer to marry a [male] dog or a bitch”.

5 Luvunu, pharmacist.
... the cases of those whom we sent to Switzerland en 1977 and to other large international hospitals and who returned home practically dead. Today we can accept in hindsight that some of them died of AIDS. We can also mention the case of foreigners.¹

Even today, the idea of contamination from abroad continues to have its followers but it now refers to other African countries. In 1996 Professor Kapenda from the University of Lubumbashi and his wife died. According to their friends, Mrs Kapenda had contracted AIDS during business activities which had been conducted, for several years, between the Congo, Zambia and Angola.² Similar opinions were expressed concerning Joachim Konde a Lubumbashi intellectual who died of AIDS in 2000. According to Kiama Mbumba, a Lubumbashi housewife, Konde was infected in Kasamayi close to the Angolan border, where he had gone to trade.³

According to statistics collected by Claire Bisseker,⁴ the number of soldiers who were HIV positive was lower in the Congo and neighbouring countries than in Rwanda, Uganda, Zambia and South Africa. During the periods 1987-1989 and 1990-1994 the number of HIV-positive people was between 3 and 5% and between 5 and 6.5% in the Congo, between 23 and 26% and about 20% in Uganda, 11% and between 22 and 27% in Zambia and 1% and 14% in South Africa. In 1998 the number of HIV-positive adults was 4% in the Congo, 6.4% in Congo-Brazzaville, 13% in the Central African Republic, 2.8% in Angola, 0.9% in the Sudan, 14% in Uganda, 11.3% in Burundi, 13.0% in Tanzania and 27.9% in Zambia.⁵

The argument that AIDS is of foreign origin is reinforced by the fact that the number of people who are HIV positive was higher in urban areas and in border towns than in rural areas during the early years of the epidemic. AIDS gradually spread from the towns to infect villages. Indeed, discouraged by an illness that was incurable, some patients left the hospitals to seek traditional treatments which were much sought after as the many accusations of witchcraft would seem to prove. In our own family we could mention the case of an aunt who returned to her village at the invitation of some relatives who lived there, as her husband and her family no longer knew what to do with her. Covered with shame, some sick people preferred to leave town, as Motanda Ngani mentioned with regard to a classmate.

Nana came from the Equator. We were fellow students in the class of political and administrative sciences. In 1988 it was suspected that she had AIDS. Even though she had completed her second year of studies, she did not return to university after the vacation. We heard that she had gone to live with her grand parents in the village where she died several months later.⁶

The return of the sick to their villages has been a common phenomenon in Africa since the colonial period⁷ and is often clandestine. The reason for treatment in a cultural milieu is psychological. The healer is seen not only as a doctor but also as someone who possesses the power to invoke the spirits of the ancestors. The treatment which he prescribes uses not only material substances but also resources from the cosmic or immaterial world.

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¹ Elimá (30 June 1987), 6.
² Mrs Lupwe, employee of the University of Lubumbashi, interviewed on 10 June, 2003 (in Lingala).
³ Mrs Mbumba, housewife and friend of the widow Konde, interviewed on 6 May 2003 (in Lingala).
⁶ Ngani Motanda, civil servant in the Head Office for Income Tax in Katanga Province, interviewed on 17 August 2003 in Lubumbashi (in French).
⁷ See César Nkuku Khonde and Sakatolo Zamebe Kakoma, “Relations dans la prise en charge sanitaire des populations urbaines et rurales en République Démocratique du Congo”, Lubumbashi médical, 2 (1999), where this phenomenon was introduced and analysed.
According to African beliefs, the illness is not only the result of the dysfunctioning of an organ brought about by a material cause, but can also be due to an intangible cause or force.

**Seroprevalence data**

It is not easy to measure the progress of AIDS in the Congo since 1983. Figures for those who are HIV positive will remain vague until systematic investigations are undertaken as was the case during the colonial period for sleeping sickness, malaria, bilharzia, leprosy and many other diseases. Because of the breakdown of administrative services for several years after independence, we are obliged to rely on data collected from testing units and hospitals. The Congolese population is reticent regarding blood tests. Even those who know that they have AIDS prefer to conceal their condition as Dr Faustin Malele points out:

HIV positive people do not always accept that they are positive and continue to worry about what others will say. Others are embarrassed about coming to our waiting rooms and prefer to remain in their motor cars until called by the doctor, with whom they have made an appointment by telephone. Most of our patients are in a very advanced stage of the disease.¹

This is what leads Dr Kakoma to say that official statistics for HIV represent only the “visible part of the iceberg”.² Published data represent approximations. The most accurate data have been collected by doctors from patients that they see in their consulting rooms. It should be added that, until recently, few laboratories were able to perform blood tests and that the nature of AIDS continued to be poorly understood by many sectors of the population, including some members of the medical corps.

This confusion concerning the nature of the epidemic is expressed in the song **Attention na sida:**

Maladi nyonso to bosani mama. Mutu azwa maladi balobi sida. Mutu azwa fièvre balobi sida. Mutu akonda balobi sida. Mutu akufa, balobi akufi na sida.³ (We have forgotten all illnesses. When someone is sick it is said that he has AIDS even if he has only a high fever. And when he dies, it is because of AIDS.)

For all these reasons it is difficult to measure the development of AIDS in the Congo. Nevertheless, we know that in spite of the efforts expended since the 1990s AIDS has continued to spread. From 1986 to 1997 the level of HIV in adults has been estimated at approximately 4% according to serological data gathered throughout the country.⁴ Surveys amongst women in certain towns and cities indicate a somewhat higher figure. In 1988 HIV amongst women was 11.4% in Kinsangani, 7% in Kinshasa and 4.4% in Mbuji-Mayi.⁵ The extent of the infection in women in child birth in Lubumbashi was 5.8% in 1996.⁶ The same level was observed in Kinshasa in 1988. In 1995 it was 7.2% in Kisantu.¹

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³ In Lingala. Moreover real scientific investigations concerning the extent of AIDS in the Congo were only undertaken and published in the Congo during the 1990-2000 decade. Before that, all scientific conferences about HIV/AIDS held in the Congo, by nationals as well as foreigners, did not indicate the characteristics and exact means of contamination of AIDS.
⁶ B. Kabila, K. Banza, K. Ngoyi, S. Kakoma, “Aspects épidémiologique de l’infection par le VIH chez la parturiente de Lubumbashi”, *Congo médical*, 3/3 (September 2001), 212. The same level was indicated by
In the testing centres the levels are higher. In the laboratory of the Regional Centre for the Fight Against AIDS in Lubumbashi, for example, 305 people out of the 592 who voluntarily presented themselves between December 1996 and June 1997 for different reasons (fear of infection, blood donation, marriage plans, trips, pre-operative examinations), that is, 50.6%, were declared to be HIV positive. The retrospective results of 1724 cases of patients hospitalized between October 2000 and March 2001 in the wards of the two hospitals in the town of Lubumbashi allow one to measure the relative importance of AIDS in relation to other illnesses calling for hospitalization in Lubumbashi. Malaria was the most frequent cause of hospitalization (25.75%), followed by AIDS (10.10%), gastroenteritis (7.71%), pulmonary tuberculosis (7.60), pneumonia (5.57%), severe arterial hypertension and cardio-vascular problems (5.22%). Taken together, respiratory ailments (pulmonary tuberculosis, pneumonia and pleurisy) were in second place accounting for 15.95% of hospitalized cases. Combined with gastroenteritis and encephalic meningitis they represent 26.79% of the cases. If account is taken of the systematic testing and the fact that these pathologies occupy a prime place amongst opportunistic infections in Lubumbashi, one is justified in thinking that an appreciable portion of these cases can be laid at the door of the HIV/AIDS infection.

Historical and social factors

The study of social, cultural and political factors allows for a better understanding of the development of the epidemic in Congolese society. Poverty, socio-political problems and socio-cultural behaviours are amongst the most important factors:

The high level of HIV/AIDS [...] is linked, amongst other factors, to the decay of morals [...] to the absence of effective counter measures [...] and to poverty. The impact of a series of wars [...] also needs to be evaluated.¹

All these factors should be considered together. It is known, for example, that sexual behaviours are influenced by poverty. This is the case with prostitution which, as is well known, played an extremely important role in the introduction and spread of HIV in the Congo and the rest of Africa. This fact has been recognised since 1985:

From Kigali to Kinshasa 90% of prostitutes have encountered the virus. In Nairobi, 7% of the ladies of easy virtue were directly affected in 1980; this figure rose to 51% in 1984.²

In the Congo prostitution is a phenomenon of colonial origin. Colonial ideology equated the migration of women to the towns with a desire to lead a life of freedom. Only married women were allowed, in specific situations, to rejoin their husbands in the towns. At the end of the recession of the 1930s the authorities created the category of “indigenous, adult and able-bodied women theoretically living alone”. The women thus defined were subjected to a tax of fifty francs which was equal to the salary of a “boy” for ten days’ work. Despite the legislation, however, single women migrated clandestinely and gradually became more

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numerous that married women: in Kinshasa, for example, of the five thousand black women who were registered, only three hundred fifty-eight were legally married.\(^1\)

Several reasons are given for women migrating towards town. Firstly they came in order to satisfy the needs of the Europeans. Up until the 1920s, the distribution of the European population in the colonial towns of the Congo was very uneven. In Kinshasa, for example, a high proportion of the six hundred European women in the town were Catholic nuns, whilst the vast majority of the two thousand five hundred European men were single. The majority of them chose girlfriends or temporary wives from amongst the black women. According to André Chalux it was common practice, especially amongst the high-ranking colonial civil servants of the time to have a négresse.\(^2\) In the film Bakandja, martyr chrétien all the whites portrayed had black wives. It was only towards the end of the 1920s, because of pressure from the missionaries, that the black mistress ceased to be seen as a sign of social success and disappeared from the public arena. Whereas the public flaunting of a négresse became unacceptable, clandestine contacts multiplied especially during the crises of the 1930s. The number of abandoned coloured children rose from 108 to 191 between 1932 and 1934\(^3\). One might well claim that prostitution, in Kinshasa at any event, was due to the demographic imbalance of the Europeans.

After the Second World War, the phenomenon of “free women” became more visible. These women targeted not only whites but also salaried blacks. They took great care of their appearance in order better to seduce the men, a fact mentioned by the Centre extra-coutumier of Elisabethville (Lubumbashi) during the 1940-1950 period:

> the majority of women theoretically prefer to remain single and detest a regular matrimonial situation. These women spend most of their days walking around in order to see if there have been any arrivals of new women’s clothing. They are always the first to buy new outfits. From morning to night, they do nothing but dress themselves in beautiful and new clothes so as to please the men.\(^4\)

This life style continued after the colonial era. Aimé Mambou-Gnali described it in the following way in 1967:

> Normally, she lives with her mother or any other female relation, an aunt or a sister who would do the shopping, the cooking and look after the children, in short, run the house. The ndumba would dress herself up and rush round town unearthing new fabrics and the latest beauty products, placing orders with the jeweller, trying on outfits at the seamstress, having her hair braided by her friends with whom she would chatter away or she would go and parade herself in the bars.\(^5\)

The so-called free women were a source of inspiration for popular musicians. Every aspect of Congolese prostitution is featured in modern popular music. In 1968 Jean Bokelo noted in a song that prostitution attracted many women even those who were married:

> Maman nalinga na fanda ndumba, bandumba mpe bazuaka, bandumba mpe balataka. Nalembi ibala ya kosuanisa ngai (Mummy, I want to become a ndumba, I want to become a prostitute. The ndumba earn their living. The ndumba dress smartly. I am tired of this life of arguing.)

The attraction which prostitution held for married women also testified to their husband’s inability, poor as he was, to maintain the household. Since the 1970s – the situation still exists although it is showing a decline – women who desired to be kept chose a


\(^{2}\) André Chalux, Un an au Congo belge (Bruxelles, Libraire Albert Dewit, 1925), 128.


“safe man”. This is the “second office” (deuxième bureau) phenomenon. A rich man was obliged to have a concubine, about whom his wife knew nothing, and whom he kept as well as though she were his own wife: he paid her rent and other needs but rarely spent the whole night with her. This is the theme of a song by Mujos in 1965: Ngai Marie nzoto ebeba (I, Marie, with my badly treated body). The composer allows a ndumba to speak directly to the wives of her clients: “The fault is that of your spouse, not mine; they know that I am single. Tell them to stop coming to see me every night and demanding that I open my door to them.”

These women feel themselves to be free and, usually secretly, engaged in sexual relations with other partners, as Mongampey recounts speaking of one of his cousins:

My cousin had a second wife who was Coloured. He had provided her with a flat and spent every evening with her, leaving at about 10 or 11 o’clock. One day, the maid told us in all innocence, that after my cousin had left, a young man who claimed to be the brother of the woman would regularly visit. After much discussion with our cousin, we persuaded him to check out the situation by asking the maid, who slept on the premises, to leave the front door of the flat unlocked. That evening, we accompanied our cousin to his second wife and pretended to leave at the normal time. We came back at midnight and caught this woman red-handed. This marriage was terminated the very same day.

Many kept women became extremely rich, especially those who practised likelemba (putting their money into a common, shared fund which allowed all the participants to benefit from the annuity, also called tontine in West Africa). They became involved in independent activities. Many specialised in regional or national trade, even international wholesale trade, exporting and importing goods from Europe and other African or Congolese towns. These women believed themselves to be independent of men and took the initiative regarding sexual relations. They attracted young men. This phenomenon became so common that in 1985 Franco Makiadi Lwambo wrote a song about it which rapidly became a best seller: Oh Mario!

Until recently, relationships between men and so-called free women were, on the whole, tolerated by Congolese society. In Kinshasa as in Lubumbashi between eight and nine out of ten salaried men or those who lived from a lucrative activity would have maintained, between 1970 and 1980, a “second office” amongst the town’s prostitutes. The chances of contracting and spreading sexually transmitted diseases, including AIDS, were legion.

Numerous opportunities for sexual contact presented themselves to the young. These were increased by poverty. My research amongst former and present students at the University of Lubumbashi led to the following conclusions:

Stories collected from the Kassapards, former and present students of the University of Lubumbashi show how the youth of the Democratic Republic of the Congo have gradually been immersed in conditions of worsening poverty which prevent them from living in better student environments. Almost all their escapades, their leisure activities and their other behaviour sufficiently show how they are governed by their precarious situation. Faced with difficulties of subsistence, women students in particular are obliged to sell themselves, to defile themselves. Young men and women, because of the

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1 Mujos is the nickname of a band leader “OK Jazz” in Kinshasa. At about the same time Lwambo Makiadi composed a song entitled Locataire (Tenant) in which he explained that the tenant rented the woman’s sex as he would do for a flat. The man should avoid hurting the woman lest she decide to break the contract and go with somebody else.

2 W. Mongampey high ranking civil servant, interviewed on the 25 November 2003 (in Swahili).

3 The man in question is Mario, a young university graduate who was jobless but good looking and who was taken as the main concubine by a woman old enough to be his mother who had children from previous relationships. She housed him in her own home and looked after him as a husband would his wife. Mario practiced the same kind of indiscretions as would a woman regarding her husband until he totally exasperated his keeper.
precariousness of their lives, become the victims of many current evils: STD and abortion, for example, are common amongst students at the University of Lubumbashi.

The same theme is to be found in the song *Attention na Sida*:

Girl student, don’t allow yourself to be carted off by a stranger. Beware of the money that you are looking for, it could lead you into danger. Be careful of numerous or casual partners.

Since 1990 poverty and precariousness have increased in the Congo. The GNP which was at 307 US$ in 1987 fell to 97 US$ in 1997. During this period, social upheavals and wars led to massive upheavals amongst the population. The countries involved in the war which tore the Congo apart from 1998 as well as those which received the refugees have been marked by a level of HIV significantly higher than previously.

The military presence in these countries reinforced the level of HIV in the Congo because of the sexual violence perpetrated by the armies during combat or because of the relations which the soldiers had with the population during periods of occupation. Sexual violence is indirectly mentioned in the testimony of these women:

We escaped after having negotiated with the rebels. We were obliged to live with them during the time that they remained in the place where they kept us prisoner. We were allowed to leave on the day when they were preparing for new combats.

Accounts collected gathered by Hervé Cheuzeville from child soldiers are even more explicit:

On 6 October 2002 in Mambasa, Virginie, a woman whom Father Silvano had married a few days previously was kidnapped by soldiers right in front of her husband. A young girl of twelve was raped in full view of the public. In town, pillaging and rape went on all day, and into the night and the following days. Even girls of eleven and twelve were gang raped by gangs of drunks. In Bambu (a Lendu locality) the Hema soldiers went into a convent. Inside the convent, the young postulants who were all Lendu, were raped by Commandant Abenga and his men.

Apparently these rapes were committed by the local militia but the testimony of a young boy called Gaston, of Katangan origin, implicated foreign soldiers:

The young Katangan boy saw something of other monstrous crimes about which he didn’t want to speak. Amongst other crimes, there were gang rapes of women and young girls in which he and the other children were forced to participate. Their forced participation in all these crimes was aimed at toughening them up according to the Rwandan officers.

From the following testimony it is clear that sexual violence was part of the military training received in the Ugandan and Rwandan army bases:

The five months that Simba and his comrades spent in Kyanwanzi (a military base in Uganda) were months of hell. Filth, discomfort, malaria, malnutrition and cruel treatment were their daily lot. But it was even worse for the few girls who formed part of their group for they had to submit to the unbridled sexual appetites of the officers and other ranks as well as their own comrades.

The child soldiers grew up in an environment which encouraged the spread of AIDS. Hervé Cheuzeville, who was in Uganda at this time, gives an account:

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1 Nkuku Khonde “Poverty, sexuality and opportunities for AIDS/STDs in the memory of the Kassapard (1970 to 2000)” paper read at the “AIDS in Context” International Conference, University of the Witwatersrand, Johannesburg, 4-7 April 2001.
4 *Ibid.*, 253
When I arrived in Galu, I discovered the hospital. The HIV/AIDS virus had found, in the northern Ugandan situation, a more than favourable breeding ground for devastation. The existing promiscuity was certainly a contributing factor.¹

Zimbabwean, Angolan and Namibian troupe who fought alongside the Kinshasa government apparently also contributed to the spread of AIDS. It is believed that these soldiers had relations with Congolese women. When it came to leaving, many of these women were in tears. As the Zimbabwean soldiers were well paid, they were very attractive to the Congolese women, especially those who had been displaced because of the war. Before this, these same women had established relations with the mercenaries involved in the war.

Another factor is the presence, in the military camps, of women whose husbands had left for the front. In order to survive, these women were obliged to sell their bodies to other soldiers and to students. In 2000, the University of Lubumbashi authorities were obliged to destroy the kiosks which served as shops or restaurants during the day. At night time they became meeting places for the students and the women of Kassapa camp whose husbands had gone to the front. They charged 100 Congolese francs (0,1US$) a time.²

To the factors which are linked to sexuality and poverty, one must add those from the cultural domain. Almost all the prostitutes encountered in Kipushi and Lubumbashi by Bansoba Detty use intra-vaginal substances which dry out, inflame and narrow the vaginal passage.³ This practice, borrowed from the tradition of certain Congolese people, increases sexual pleasure. The client will return more willingly to this woman who gives him the impression that he is deflowering a virgin.

The fight against AIDS

The fight against AIDS in the Congo began the day when the existence of the disease and its treatment were confirmed. A Central Office for the Fight Against AIDS was established in 1986 in order to identify and monitor the disease and to put policies of prevention in place, mainly in blood banks. This structure, principally attached to the Ministry of Public Health, later became the National Committee for the Fight Against AIDS. From the outset it operated from Kinshasa and it was only later that provincial centres were established.

The central office coordinated the awareness campaign from Kinshasa. Suggestions for prevention were broadcast on radio and later screened on television and awareness teams were sent to provincial capitals and other large towns to give lectures on AIDS. Until 1990 the content of the awareness messages was the same as the song Attention na Sida:

Workers, bureaucrats, managers in workshops, in factories when you are chatting, spread the message about the fight against AIDS.
Let he who knows more inform his brother. Do not be embarrassed, time flies and each day people are dying, victims of AIDS. A good cure is information, the best cure is to protect yourself [...]. Priest in church, ministers during worship, rabbis in their synagogues, imams in the mosques you all have a responsibility, an enormous responsibility towards society: use your positions to preach what society needs to know about AIDS. Do not be ill at ease. This is your duty [...].
Educators, instructors, teachers in schools, in the classroom, in holiday camps as soon as you have a spare moment, speak about AIDS [...].
Educators in schools, colleges, high schools and even universities, parents are counting on you for your support [...]
Parents, do not turn away, talk to your children, tell the youth everything that you know about AIDS [...].

¹ Ibid., 93
² Author’s observation.
Political leaders, use radio, television, newspapers to inform the population of the danger of AIDS. You must tell them how to protect themselves.

This message targeted everyone. At the beginning of the 1990s special awareness groups like JAMST (Jeunesse anti-MST/Sida) and SWAA (Society for Women Against AIDS) were organised for select groups. These groups organised lectures and distributed posters. It was at this time that the first posters appeared in Lubumbashi stressing the use of condoms.

During the same period, non governmental organisations began to associate themselves with the National Programme for the Fight Against AIDS by supporting health and training centres. Such was the case of Médecins Sans Frontières/Belgium (MSF/B) which, from 1993 paid special attention to the treatment of sexually transmitted infections (STIs) in Kinshasa. This choice was justified, according to the supervisor of the health centres associated with MSF, because of the role played by sexual diseases in the transmission of the virus. According to a recent study, two thousand five hundred new cases of STIs are registered every month in Kinshasa in the health centres associated with MSF.

In 2000, the strategy changed. The principal role of the National Programme for the Fight Against AIDS became the coordination that co-ordination of the activities of associations and NGOs involved in the fight against AIDS. Several of these NGOs henceforth become involved in collective awareness and interpersonal communication. In recent years, the awareness campaigns have become more obtrusive: publicity spots are broadcast on radio and television whilst the NGOs have left their offices and gone into the streets to become associated with orchestras and stars of popular theatre. In Lubumbashi, for example, there are periodic motorised campaigns which attract public attention because of the diversity of the presenters. In order to make the public more aware, the NGOs produce short, improvised plays in the streets. Françoise Delait describes a show which was recently produced by MSF’s IEC-IST/SIDA Project in Kinshasa:

Our friends’ plan of attack was to surprise people. The actors were quite simply going to deceive the spectators by simulation in the middle of the market. A woman was carrying a sick person on her back and she collapsed in the middle of the road, crying out. Suddenly everything was in turmoil, people flocked from everywhere. Everybody wanted to see, to offer suggestions, there was running in all directions and this in less than three minutes. There were more than fifty people gathered around the two “players”. Then the presenters arrived, easily identifiable by their T shirts. The woman complained about symptoms similar to STI. The appeal was obvious. Why not take her to the nearby health centre which treated STIs? Awareness teaching began when, suddenly, the “ill person” stood up, completely cured. A wave of shock swept through the crowd. They understood but couldn’t quite grasp that they had been taken for a ride. Discussions began. Each member of the Tam Tam group of awareness teachers had eight or ten people round them.

Since 2001-2002 the NGOs have also adopted an Interpersonal Messages Programme which consists of organising awareness campaigns on “Information, Education and Communication” (IEC) or “Communication for a Change in Behaviour” (CCB) which target groups such as sex workers or students.

The work method of IEC teams on the STI/AIDS project is described by one of its developers in these terms:

Our work starts with the identification and localisation of people who live with multiple partners. These are mainly sex workers […] These targeted people are usually found in hotels, bars or areas where

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2 Marc de Rijcke, “Projet sida, MSF s’attaque aux IST pour freiner le Sida à Kinshasa”, Bonobo, 10 (second quarter 2003), 4.
3 Françoise Delait, “IEC IST/SIDA project, the Tam Tam group in action against STIs”, Bonobo, 9 (April-May 2003), 4.
those who have been displaced by the war live. Some of the work is carried out during the day in the hotels where the sex workers live, from Monday to Thursday. The rest is done at night, during the weekends, Friday and Saturday [...] in the bars and discos. Using a magic lantern, we show them pictures of infections. With a wooden penis, we show them how their partners can put on a condom. We also have pamphlets on STIs, cartoons, posters and condoms which we sell them at reduced prices. At the end of an awareness session we distribute reference cards (on which the relevant health centres are marked) which allow them to be treated at reduced rates in the participating health centres and also allow them to have a free HIV/AIDS tests [...] During our nocturnal rounds of the bars and discos we asked the sex workers who do not live in hotels to give us their addresses so that we could visit them during the day in order talk to them.1

Regarding the awareness programmes for the youth, we can mention the work carried out by the NGO World Production/School Prevention AIDS and Education Children (WP/SPAEC) on the campus of the University of Lubumbashi. They work in collaboration with other NGOs such as the Forum Provincial Sida (FOPS1), l’ABF/ND, l’AMOCONGO, l’ASF/USAID. The WP/SPAEC carried out two awareness campaigns on STI/AIDS in university residences during 2001 and 2002.

During the 2001 campaign, talks, film shows and debates were organised in all the residences and lecture theatres. The WP/SPAEC also undertook to train educators amongst the students.2 The second campaign took place from 8 to 25 April 2002. It consisted of an IEC (Information, education and communication) campaign as well as a CCB (Communication for Changing Behaviour) with talks/debates, demonstrations on the fitting of condoms on wooden penises, promotional sales of condoms, films shows followed by debates, announcements using loud hailers and interpersonal communication between students and counsellors in the residences. Thirty qualified counsellors visited the universities, the lecture rooms, the residences, the administrative buildings and the suburbs close to campus to spread the message for the prevention of STIs and AIDS.

The WP/SPAEC campaigns were followed up with the establishment of a permanent branch on the campus. The following table gives an idea of the work carried out by this IEC team:

### Students sensitised by the CCB at the University of Lubumbashi (2002-2003)

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Source: Monthly reports from the WP/SPAEC Campus branch, May 2002 - Nov. 20033

Each month, between twenty and two thousand five hundred students were individually contacted by the educators, most often in the residences, and a message on the prevention of STIs and AIDS was passed on. During some of the months, the table also shows the number of students who were contacted in the lecture rooms and in public places on

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1 Mwayuma Kahashi, Riva and Kazadi wa Mwanza, Annie, “IEC/IST/SIDA au Kitanga”, Bonobo, 5 (first quarter 2002). Note that amongst the teachers who were recruited and trained by MSF there were ex-sex workers so as to allow the other teachers the benefit of their experience. Cf. Lolo Losongo, “Lutte contre le sida et les IST; l’équipe IEC pour la sensibilisation est enfin complète”, Bonobo, 6 (second quarter 2002), 2.

2 Lettre 17, WP/SPAEC, of 20 February 2002 sent to the chancellor of the University of Lubumbashi by Adelard Mutumbo, director general of WP/SPAEC, requesting permission to organise a second awareness campaign.

campus. For these awareness campaigns, the educators used illustrated leaflets. June 2003 was the most active month.

In November 2003, the month of World AIDS Day, a door to door awareness campaign was organised in all the University residences with the following themes: condoms as a means of prevention, the fight against the practice of initiation using razor blades and VCT (Voluntary Counselling and Testing).¹

The impact of this WP/SPAEC awareness campaign can be seen in the increase of use of condoms in student circles in Lubumbashi. From April 2002 to November 2003, 56,520 condoms were distributed on campus at an average of 2826 condoms per month.²

A second result of the awareness campaigns was the increase in the number of students who were tested for HIV. The VCT campaign was launched in March 2003 with the support of the Amo-Congo NGO in the context of “the fight against HIV ignorance”. The number of students who received appropriate VCT from Amo-Congo grew from 30 to 50, 70, 100, 170 and 190 in March, April, May, June, July and August 2003 respectively.³ In subsequent years this NGO continued to grow with the financial support of the Programme national multisectoriel de lutte contre le sida (PNMLS). This programme funds various programmes for PWAs and AIDS orphans. Numerous role-players, including muslims, are involved in this programme.

**Rejection and exclusion**

Sources, written as well as oral, to which the remainder of this article refers, provide useful information on popular replies concerning HIV/AIDS. We will review the main ones: exclusion, rejection, despair, classification of AIDS as a divine punishment.

The majority of Congolese see AIDS as a disease of the Other. It is the Other who is responsible for the plague, never oneself. The first to be accused are the prostitutes. At home, the husband blames his wife (see the case of the Kapenda couple). The wealthy are also blamed because they socialized with foreigners. Young people believe that AIDS is an adult disease.

People who have AIDS tend to distance themselves from society. Believing that society condemns them, they feel ashamed despite the fact that certain campaigns for the fight against AIDS spread the message that having AIDS is not shameful. A Swahili advertisement broadcast by the Prudence brand of condoms states: *Hakuna haya na Sida* (Do not be ashamed of HIV/AIDS). The feeling of rejection experienced by those who live with AIDS comes from the fact that they are stigmatized by those close to them. The over-riding feeling is that it is a waste of time to care for an HIV positive people because they would die in any case.

In his song Franco Lwambo evokes these behaviours of exclusion and rejection:

AIDS has divided our nation
AIDS has destroyed my home.
AIDS has broken up my family.
My family and my friends avoid me
Because I have just been infected with AIDS.
Those closest to me have abandoned me.
In whom can I confide?
My entire family is avoiding me
Because I have AIDS.
Only my mother takes trouble over me.

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¹ WP/SPAEC campus report, November 2003.
Once again she cares for me  
As she did when I was a child  
But she cares for me with bitterness.¹

Excluded from the benefit of tritherapy, those who are HIV positive adopt an attitude of resignation which sometimes hides a state of despair. Some are angry and practise a “scorched earth” policy where they deliberately infect others. Let the floods come after me!! It is to them that Lwambo refers when he sings “You, my brothers and sisters who have AIDS, do not wilfully seek to infect others. Oh mawa!”

Africans are very religious. They tend to seek answers for what they do not understand in the realm of the supernatural. The composer of Attention na Sida is no exception. Maladi yo maladi oyo sida, nzambe apesi biso etumbu mama. (“Oh you, disease of AIDS. God is punishing us.”) In the same song he pleads with those priests who hear confession to intercede with God so that He may deliver the Congolese from AIDS.

Conclusion

Oral testimonies confirm the AIDS, identified in the Congo in 1983, had been present amongst its people from the early 1970s if not earlier. The African origin is hotly disputed. HIV antibodies had been found in the blood of a sick man who was hospitalized in Leopoldville in 1959.² But this fact does not prevent many of our informants from believing in the foreign origin of the epidemic.

Reliable data concerning the evolution of HIV in the Congo are lacking. Information exists concerning specific groups of people. What is certain, however, is that the number of cases of AIDS continues to increase. Overall, the rate of HIV in the adult population was estimated at 4% during the 1986-1997 period. It was higher in women – 4.4-7% – than in men.

Sexual behaviour linked to prostitutes or those who are close to them has contributed to the spread of AIDS. History has shown that there is correlation between prostitution and poverty. Colonisation is responsible for current forms of prostitution. The business of selling sexual favours was practised by poor urban women but also suited men who had “second offices”. Socio-political problems not only reinforced prostitution and poverty but increased sexual violence and moral depravation, exposing the public even more to the dangers of HIV/AIDS.

Since its appearance AIDS has attracted the attention of the authorities but the fight against the epidemic has only been organised slowly. The most effective strategies seem to date from 2000 and 2001. However, the campaigns against AIDS have met with popular resistance and are embedded in behaviours and attitudes of rejection and exclusion.

(Translated from the French by Carole Beckett)

¹ Translated from Lingala.
Part Six

Bibliography
The History of HIV/AIDS in Africa: a Bibliography

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1. Introduction

In the enormous and growing HIV/AIDS literature, biomedical HIV/AIDS research is well established. In order to understand the complexity of factors in the transmission, treatment, care, and support of HIV/AIDS, there have been calls for more social scientific HIV/AIDS research. Despite the important research in the social sciences, research findings are not widely circulated and our understanding of the social factors remains fragmented.

A review of the literature shows that various professions and disciplines have contributed to the history of HIV/AIDS. Initially, the history of HIV/AIDS emerged from studies in medicine, sociology, anthropology, political science, economics, and activist theory. Moreover, journalists played an important role in the early documentation of the epidemic in the United States, Europe, and Africa. While these multidisciplinary approaches added vitality to the field of HIV/AIDS, historians had a unique contribution to make.

The historical analysis of HIV/AIDS in Africa is relatively recent and limited. Since the mid-1990s there has been increasing historical HIV/AIDS research. Historians have turned their attention to the complex interaction between the historical, political, economic, social, and cultural factors that created the conditions for the emergence, spread, and management of the epidemic in Africa.

Contributors to this book highlighted the need for a bibliography of the history of HIV/AIDS in Africa, noting that there is a shortage of historical HIV/AIDS research in Africa, documentation of the existing research, and research that utilises historical methodology. In keeping with the language format of the conference and this book, the bibliography highlights the historical research of HIV/AIDS in Africa that has been published in English and French. This delineation excludes HIV/AIDS research published in other languages spoken in Africa, and East and North Africa receive less attention than West, Central, and Southern Africa.

In making selections for this bibliography, it was decided to include historical research, as well as research from the medical sciences, social sciences and humanities that provided historical insights, utilised historical methodology, or contributed to the historical
documentation of HIV/AIDS in Africa. This bibliography has three sections that deal with the history of HIV/AIDS:

1. Introduction to International HIV/AIDS Research,
2. Anglophone and Francophone HIV/AIDS Research in Africa, and
3. Other HIV/AIDS History Resources in Africa.

The first section provides introductory references to research areas and historiographical issues as they relate to the history of HIV/AIDS, primarily in Europe and the USA. The second section provides an alphabetical bibliography of Anglophone and Francophone HIV/AIDS research. This section forms the bulk of the bibliography and aims to provide an outline of the main research themes in the history of HIV/AIDS in Africa. The third section provides references to other sources of information that might be useful to historians and researchers in the social sciences.

A few observations stem from the Anglophone and Francophone HIV/AIDS research bibliography.

One, the bibliography begins on 8 January 1983 with the letter in the *Lancet* that suggested that HTLV is linked to Africa (Fleming, 1983). From 1983 onwards, researchers documented AIDS cases in various regions of the continent, mostly in Central and West Africa. For reasons of brevity, it was decided to highlight these early papers up to 1986 even though there are many important papers dealing with the same theme in subsequent years. For example, the retrospective studies of AIDS cases in Africa between the late 1950s and early 1980s (e.g. Sonnet et al, 1987; and Rémy (a-f), 1993).

Two, in 1987 there is a shift in the HIV/AIDS research in Africa, from purely biomedical to social scientific research. The role of cultural factors in the transmission on AIDS in Africa was explored (Hrdy, 1987).

Three, this important shift to social scientific research was followed by the exploration of further social issues and HIV/AIDS in 1988. Research was published that dealt with the historical roots of AIDS in Africa (Dawson, 1988), the sociological aspects of the disease (Piot & Caraël, 1988), and public health strategy (Etchepare, 1988). The examination of public health issues and HIV/AIDS followed the research trends that had been established earlier in the decade in the USA and the UK.

Four, in 1989, there was a marked increase in social scientific HIV/AIDS research. There was research dealing with socio-political factors of AIDS (Collignon & Becker, 1989), the social context of AIDS (Caldwell et al, 1989), anthropological examinations (Epelboin, 1989), migrant labour (Hunt, 1989), the state and the allocation of health resources (Marks & Anderson, 1989), history (Larson, 1989), geography (Shannon & Pyle, 1989), ethics and religion (de Sweemer, 1989), and legal issues (Sané, 1989). In 1990, research was undertaken that examined HIV/AIDS and gender (Kisekka, 1990), sexuality Harris, 1990), and children (Preble, 1990). These early papers were important because they highlighted the social context of HIV/AIDS, set the agenda for research that followed, and challenged the predominance of biomedical HIV/AIDS research.

Five, the 1990s were characterised by a burst of social HIV/AIDS research in Africa. Some of the issues examined historically were migration, labour, state action, cultural practices, gender, manhood, education, NGOs, counselling, colonial and post-colonial health
practices and policies, the training of health care workers, law and ethics, the role of religion and the Church, sex workers, witchcraft, and historiography. Also, regional research in areas like West Africa, Central Africa, and Southern Africa was established.

Six, the social and historical research of HIV/AIDS in Africa led to the examination, and, at times, reexamination of issues like colonial and post-colonial health policies and practices, previous epidemics, traditional medicine, cultural practices, and gender. Some of these issues continue to be contested in the origin of AIDS debate, between advocates of the natural transfer theories and the iatrogenic theories.

Seven, while historical examination of HIV/AIDS in Africa is now established, significant historical research lacunae remain. This is most evident in the lack of: (1) comprehensive HIV/AIDS histories of specific countries, (2) regional and continental research that highlights and integrates pertinent HIV/AIDS themes, and (3) critical historiographical analyses of how HIV/AIDS is addressed in Africa.

Finally it should be noted that this bibliography is introductory and it reflects research found useful by the contributors to this volume and current research being conducted by the author. Omissions are inevitable but is hoped that this bibliography will contribute to future efforts to document the history of HIV/AIDS in Africa.

2. The History of HIV/AIDS: Introduction to International Research


CLELAND J. and WAY P. (eds), 1994, AIDS Impact and Prevention in the Developing World : Demographic and Social Science Perspectives (Canberra, Health Transition Centre).


EPSTEIN S., 1996, Impure Science : AIDS, Activism and the Politics of Knowledge (California, University of California Press).


HANNAWAY C., HARDEN V.A. and PARASCORDOLA J. (eds), 1995, AIDS and the Public Debate : Historical and Contemporary Perspectives (Amsterdam, IOS).


3. The History of HIV/AIDS in Africa: Anglophone and Francophone Research


CAROLINA POPULATION CENTER (CPC), 2004, AIDS in Africa During the Nineties : Malawi. A Review and Analysis of Surveys (Chapel Hill, University of North Carolina at Chapel Hill).


FALL L., 2000, État des lieux de la confidentialité partagée dans l’infection à VIH/SIDA à Dakar (Dakar, UCAD, Faculté de Médecine et d’Odonto-Stomatologie), 173 p.


GREEN C.E., 1992, “The Anthropology of Sexually Transmitted Disease in Liberia”, Social Science and Medicine, 35/12, pp. 1457-1466.


MOGENSEN H., 1995, AIDS is a Kind of Kabungo that Kills (Oslo, Copenhagen, Stockholm and Boston, Scandinavian Universities Press).


NTOZI J.P.M., ANARFI J.K., CALDWELL J.C. and JAIN S. (eds), 1997, Vulnerability to HIV Infection and Effects of AIDS in Africa and Asia/India (Canberra, Health Transition Centre).


SHAW C., 1995, Colonial Inscriptions : Race, Sex and Class in Kenya (Minneapolis, University of Minnesota Press).


SWEEMER C. de, 1989, “Ethics, Inequity, Religion and AIDS in Developing Countries”, in D’ALMEIDA L (éd), AIDS Africa/Sida Afrique, Plurale, 1/1, pp. 149-152.


VANGROENWEGHE D., 2000, Sida et sexualité en Afrique (Anvers, EPO).


4. Other HIV/AIDS History Resources in Africa

This section contains an inventory of a certain number of tools and internet sites which provide information on the social and historical aspects of AIDS in Africa.

4.1 Web Sites

AAVP – African AIDS Vaccine Programme / HAVEG  
HIV/AIDS Vaccine Ethics Group (HAVEG), University of KwaZulu-Natal  
E-mail: HAVEG@ukzn.ac.za  
http://www.saaavi.org.za/havec.htm  

HAVEG is in charge of the secretariat of the WHO-UNIAIDS working group for “African AIDS Vaccine Program”  
http://www.who.int/vaccine_research/diseases/hiv/aavp/en/  

The group was created within the WHO-UNIAIDS initiative for an HIV vaccine.
African Online Digital Library
http://www.aodl.org/becker.php
   Collection of personal research by Charles Becker into AIDS.

AIDSLAW
Réseau Juridique canadien VIH/Sida – The Canadian HIV/AIDS Legal Network
http://www.aidslaw.ca/
   Site in French and English.

Council for the Development of Social Science Research in Africa / Conseil pour le développement de la recherche en sciences sociales en Afrique (CODESRIA)
http://www.codesria.org
   The entire text of Vivre et penser le sida en Afrique/Experiencing and Understanding AIDS in Africa can be found at http://www.codesria.org/Links/Publications/monographs/aids.htm
   Texts of a recent conference on “Social Sciences and AIDS” http://www.codesria.org/Links/conferences/hiv_aids/hiv_aids.htm

Family Health International (FHI)
   amily Health International offers a variety of resources and places basic tools and products developed under the direction and auspices of FHI at the disposal of those involved in dealing with AIDS. Centres in different countries distribute many documents in various forms: printed documents, CD-ROMS, video cassettes etc.

Interagency Coalition on AIDS and Development (ICAD)
Our Peers, Our World, Our Future : Resources on HIV/AIDS and Youth in Developing
www.icad-cisd.com/content/pub_details.cfm ?ID=30&CAT=1&lang=e
   Example of a specialised bibliography.

International Network for the Availability of Scientific Publications (INASP)
http://www.inasp.info
   INASPP is an international network for furthering accessibility to scientific publications, particularly in countries of the South.
   On the subject of health consult http://www.inasp.info/health/index.shtml
   The project “African Journals Online” (AJOL) allows for access to journals which publish articles on AIDS.

World Health Organization (WHO) / Organisation mondiale de la santé (OMS)
http://www.who.org
Programme
http://www.who.int/hiv/en/
Publications
http://www.who.int/hiv/pub/en/

Popline
[http://db.jhuccp.org/popinorm/basic]
   Produced by Johns Hopkins Bloomberg School of Public Health, POPLINE is the most important database on population and health. This database contains many bibliographic references on AIDS. The history of AIDS is scarcely mentioned. On the other hand, many documents deal with the prevention, treatment, support and care of AIDS. See, for example, “Antiretrovirals and HIV/AIDS” and “Migration and AIDS”.

Population Council
http://www.populationcouncil.org
Particularly:
http://www.populationcouncil.org/hivaids/index.html
   The Population Council, in particular Horizons Project, is developing a programme of research, production and distribution of information on STD/HIV/AIDS in West and Central Africa. Many summaries and collaborative
documents containing the results of operational research are available on site or from the Population Council and RARS who collaborate with this distribution and specifically collaborate with the translation of English documents into French.

PubMed and Medline

PubMed is a service offered by the National Library of Medicine which includes more than 15 million quotations from Medline and other life science journals containing bio-medical articles published since the 1950s. PubMed includes information regarding accessing the full texts of articles referred to as well as accessing other articles on related subjects.

African AIDS Research Network (AARN) / Réseau africain de recherche sur le SIDA (RARS)
http://www.refer.org/sngal_ct/rec/rars

The African Network of research into AIDS (RARS) encourages interdisciplinary collaboration and concentrates on the biomedical and social aspects of AIDS. Its directory of addresses and publications is particularly useful for research into AIDS which has been written in French. The network is based in Dakar, Senegal. It regularly publishes bibliographies as well as thematic bibliographies. It is one of the focal points of the “Hinari Project”, an initiative of the general secretariat of the United Nations, driven by the WHO, and aimed at giving access to the major scientific journals.

Réseau d’information francophone sur le sida (SIDANET)
http://www.sidanet.asso.f

The SIDANET association aims at “improving medical information in the field of AIDS, enhancing its standing and facilitating its distribution by electronic and traditional means.” It currently offers resources and information for three African countries (Senegal, Cameroon, Mali).

Senegalese Network on “Law, Ethics and Health” - Réseau sénégalais “Droit, éthique, Santé”
http://www.refer.sn/rds

This network contains publications and conference papers on the law of health, ethics and bio-ethics in Africa. See, particularly, the headings:
“Network Activities and research” http://www.refer.sn/rds/rubrique.php3?id_rubrique=3
“Publications and articles on line” http://www.refer.sn/rds/rubrique.php3 ?id_rubrique=8

Are listed various articles mentioned in this bibliography, like, for example:

http://www.refer.sn/rds/article.php3?id_article=194

These documents are also available in English.

Save the Children
http://www.savethechildren.org/health/hiv_aids/index.asp

Sociétés d’Afrique et Sida
http://www.ssd.u-bordeaux2.fr/sas/base_doc

This database focuses on the social dimensions of HIV/AIDS in Africa, and the titles are organised by region and country. The two regional categories are North Africa and Southern Africa, and research titles are provided for forty countries. This database serves as a useful introduction to relevant HIV/AIDS research in particular African countries.

UNAIDS / ONUSIDA
http://www.unaids.org

Provides access to many documents concerning Africa which were published at different dates.

UNESCO
http://www.unesco.org

Various documents pertaining to Education, Prevention of AIDS, the problem of HIV and human rights are accessible.
UNICEF
http://www.unicef.org
Consult particularly/
http://www.unicef.org/uniteforchildren/index.html

UNIFEM
Unifem, in collaboration with UNAIDS has developed a digital library on “Gender and HIV/AIDS. This library, in the form of a CD-Rom, is accessible from the opening page:
http://www.genderandaids.org
It is a compilation of resources produced by different organizations working in the field of AIDS.

4.2. General Bibliographies

Various bibliographies – general and thematic – are available or can be composed from the information on the afore-mentioned internet sites or from other sites not mentioned here. Highly recommended are two recent general bibliographies which are particularly relevant. They deal entirely or for the most part with the social sciences and AIDS in Africa.

4.3. National Bibliographies

With the exception of the databases mentioned in the previous section, the historical and social bibliographies are not normally arranged according to region or country. Despite this, here are a few examples of national bibliographies on AIDS. An analysis shows that the majority of them mention a wide choice of documents which are only of indirect interest to an historian. These bibliographies offer the possibility of tracing the history of research into AIDS in different countries and, more particularly, of assessing the history of the reaction to the epidemic through the documents written by those who were involved.

4.3.1. South Africa

See also “Bibliography on HIV/AIDS and Migration in Southern Africa” (March 2004) [http://www.queensu.ca/sarc/Projects/AIDS/Resource.htm]

4.3.2. Burkina Faso

See also “Sciences sociales et sida” [http://www.vihinternet.org/afrique/doc]

4.3.3. Ethiopia


4.3.4. Ivory Coast / Côte d’Ivoire

See also “Sciences sociales et sida” [http://www.vihinternet.org/afrique/doc].
Sciences sociales et SIDA, [http://www.vihinternet.org/afrique/doc]

4.3.5. Senegal / Sénégal

[http://www.refer.sn/rds/article.php3?id_article=205].

See also “Sciences sociales et sida” [http://www.vihinternet.org/afrique/doc].

4.3.6. Zambia

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*Philippe Denis et Charles Becker (dir.)*  

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Part One / Première Partie — Introduction

Philippe Denis, Towards a Social History of HIV/AIDS in Sub-Saharan Africa / Pour une histoire sociale du sida en Afrique subsaharienne

The purpose of this introductory chapter is to locate the book within the field of AIDS research in Africa. Against the background of a quasi-hegemony of biomedical research the social study of HIV/AIDS has started to take prominence in the 1990s. A smaller number of authors explore the historical roots of the epidemic. As far as the social response to the epidemic is concerned, HIV/AIDS resembles many previous epidemic episodes but it is unique with regard to the nature of the disease and the amplitude of the epidemic. This chapter also discusses issues of periodisation and raises methodological concerns, concerning African sexuality in particular.

Le propos de ce chapitre introductif est de situer le livre dans le champ de la recherche sur le sida en Afrique. Face à la perspective quasi-hégémonique de la recherche biomédicale, l'étude du VIH/sida par les sciences sociales a commencé à prendre son essor dans les années 1990. Un nombre plus faible d'auteurs ont exploré les racines historiques de l’épidémie. Pour autant que la réponse sociale à l’épidémie est concernée, l’épidémie du VIH/sida ressemble à beaucoup d’épisodes épidémiques précédents, mais elle est unique à cause de la nature de la maladie et de l’amplitude de l’épidémie. Ce chapitre discute également des problèmes de périodisation et soulève des questions méthodologiques, au sujet de la sexualité africaine en particulier.

Part Two / Deuxième Partie — The Dynamic of the Epidemic / La dynamique de l’épidémie

Chapitre I

Michel Caraël, Twenty Years of Intervention and Controversy / Face à la mondialisation du sida : vingt ans d’interventions et de controverses

The discovery of HIV in 1983 has been accompanied by an intense debate on the mode of transmission of the virus, the risks factors associated with the infection and its root causes. As time went on, the responses to the epidemic evolved. At first, emphasis was laid on the infected people and the medical control of the disease. More attention was later paid to the concepts of individual risk and groups at risk with the underlying ideology that peoples with risky behaviours had the power to make informed decisions. More recently, this conceptual framework began to include the notions of “situations at risk” and socio-economic vulnerability with the acknowledgment that individual attitudes are socially determined. International HIV/AIDS policies often faced resistance or indifference at national level. With the extension of the HIV/AIDS epidemic and their growing diversity in the world, the debate on the underlying causes of these divergent evolutions and the most appropriate responses is gaining momentum, not without ideological presuppositions.

La découverte du virus en 1983 s’est accompagnée d’un intense débat sur les modes de transmission du VIH, sur les facteurs de risque associés à l’infection et sur ses déterminants. Au gré des années, les stratégies de lutte contre l’épidémie ont évolué avec au début l’accent mis sur les personnes infectées et leur contrôle dans un cadre médical; ce furent ensuite les notions de risque individuel ou de groupes au comportement à risque qui l’emportèrent, avec l’idéologie sous-jacente que les personnes aux comportements à risque ont le pouvoir de prendre des décisions sur base d’un choix rationnel. Plus tard le cadre conceptuel s’est élargi avec les notions de “situations à risque” et de vulnérabilité socio-économique qui reconnaissaient les contraintes qui pèsent sur les comportements. Avec l’extension des épidémies de VIH et leur grande diversité dans le monde, le débat sur les déterminants de ces évolutions divergentes a repris avec intensité.
Chapitre II


Sub-Saharan Africa is the continent in the world worst affected by the HIV/AIDS epidemic. Over 90% of adults in Africa acquired their infection through heterosexual contact. There are however large variations in HIV prevalence between different regions in sub-Saharan Africa. Eastern and Southern Africa are more severely affected than West and Central Africa. HIV infection has probably been present in African populations for many years before AIDS was first described in 1981 in the United States. The first cases of AIDS seem to have appeared in Uganda and Tanzania shortly after the liberation war in Uganda in 1978-1979, but antibodies against HIV were detected in a serum sample collected from a Kinshasa resident in 1959. The course of the HIV epidemic has been extremely variable in different regions of sub-Saharan Africa and it is very difficult to reconstruct these epidemics. HIV epidemics are the result of a complex interplay of sexual behavioral factors that determine the probability of having intercourse with an HIV infected person, and biological factors that influence the transmission of HIV during sexual intercourse. In the multicentre study on factors determining the differential spread of HIV in four African cities, for instance, it appeared that biological factors that enhance the transmission of HIV infection during sexual intercourse, probably outweighed differences in sexual behavior in explaining different prevalence rates between Eastern and Southern Africa and West Africa. These biological factors included lack of male circumcision and infection with herpes simplex virus 2 (genital herpes). Several cultural and socio-economic features of African societies conspire to enhance the vulnerability of African populations to HIV, including the subordinate position of women, impoverishment, rapid urbanisation and modernisation, and last but not least wars and conflicts.


Chapitre III

Alex de Waal & Alan Whiteside, AIDS, a Darwinian Event? / Le sida : un événement darwinien ?

In this chapter the authors view the HIV/AIDS epidemic as a complex systemic change in human ecology, unleashing secondary impacts that have demographic and feedback loops into the epidemic itself. They suggest that AIDS is an event of such magnitude as to assume proportions of a “Darwinian event”. The aim of the paper is to stimulate debate and inspire disciplines new to the area to research the epidemic and its consequences. The authors examine whether AIDS fits Darwin’s notion of “survival of the fittest”, taking into account not only genes, but memes (a replicator similar to biology’s genes, in the human brain) and their role in survival and reproduction, using the examples of male circumcision and risk-taking. Looking at demographic impacts of HIV/AIDS they argue that Homo sapiens is an organism as well as part of an ecological framework contending that any change in the framework affects us, leading to a new collective adaptation. Their conclusion is that AIDS is a longwave event with structural implications for human ecology, which in turn implies that its secondary impacts will themselves be structural and sustained. In this article they speculate that we have already adapted to the virus.
Dans ce chapitre les auteurs considèrent l’épidémie du VIH/sida comme un changement systémique complexe de l’écologie humaine, déclenchant des impacts secondaires qui ont des boucles démographiques et de rétroaction dans l’épidémie elle-même. Ils suggèrent que le sida est un événement d’une telle amplitude qu’il revêt des proportions d’un “événement darwinien”. Le but de cet article est stimuler la discussion et d’inspirer aux disciplines nouvelles dans ce domaine de rechercher l’épidémie et ses conséquences. Les auteurs examinent si le sida concorde avec la notion darwinienne de “survie du plus capable”, tenant compte non seulement des gènes, mais des mêmes (un réplicateur semblable aux gènes de la biologie, dans le cerveau humain) et de leur rôle dans la survie et la reproduction, en utilisant les exemples de la circoncision masculine et de la prise de risque. Observant les impacts démographiques de VIH/sida, ils arguent du fait qu’homo sapiens est un organisme aussi bien qu’une partie d’un cadre écologique affirmant que n’importe quel changement du cadre nous affecte, menant à une nouvelle adaptation collective. Leur conclusion est que le sida est un événement aux effets à long terme, avec des implications structurales pour l’écologie humaine, qui implique alternativement que ses impacts secondaires se veulent eux-mêmes structuraux et soutenus. Dans cet article, ils spéculent sur l’idée que nous nous sommes déjà adaptés au virus.

Yves Zoa Zoa, Cattle Breeders and the Spread of AIDS in the Lake Chad Basin / Les éleveurs de bovins et la diffusion du sida dans le bassin du lac Tchad

This paper presents and explains the involvement of cattle breeders in the spatial and temporal spread of HIV/AIDS in the Lake Chad basin. These cattle breeders are subdivided into three groups: the Djafun, the Wordabé and the Akou. The paper is essentially based on statistical data collected in the field and on daily observations. Initiatives and policies have been established by different governments in the area as well as by the international community in an attempt to eradicate the disease. However, the incidence rate continues to grow approaching, on average, 14 %. The breeders are contributing to this increase. Their involvement appears to be as a result of the following factors: (i) a traditional system of breeding which is characterised by frequent and regular movements from one area to another ; (ii) a basic and low level of education ; (iii) an unrestricted system of marriage in areas to which the cattle move ; (iv) difficult access to modern information and communication technologies ; (v) lack of recourse to modern existing health care ; (vi) ignorance of the disease ; (vii) poorly run awareness campaigns. These breeders constitute a target group which has not been properly identified and which is almost unknown to the different awareness programmes. It is absolutely necessary to rectify and improve these situations if there is to be a meaningful reduction of HIV/AIDS in this region.

Cet article présente et explique l’implication des éleveurs de bovins dans la diffusion spatiale et temporelle du VIH/sida dans le bassin du lac Tchad. Il est basé prioritairement sur les données statistiques de terrain et les observations quotidiennes. En effet des initiatives et des politiques ont été mises en place par les différents États de la région et la communauté internationale pour éradiquer le mal. Mais, les taux de prévalence continuent d’augmenter avoisinant en moyenne les 14 %. Les éleveurs participent à cet accroissement. Leur implication semble donc déterminer par les insuffisances suivantes:
1. un système d’élevage traditionnel caractérisé par de forts et constants mouvements spatiaux.
2. un niveau d’instruction approximatif et faible.
3. une situation matrimoniale assez libérale en zone de transhumance.
4. le difficile accès aux nouvelles technologies de l’information et de communication.
5. le non-recours aux soins de santé modernes existants.
6. l’ignorance de la maladie.
7. une sensibilisation mal menée.
8. une cible mal recensée et presque ignorée dans les différents programmes de sensibilisation. La correction ou l’amélioration de celles-ci serait par conséquent un préalable déterminant dans la réduction sensible du VIH/sida dans cette région.

Part Three / Troisième Partie — HIV/AIDS in the History of Epidemics / Le sida dans l’histoire des épidémies

Chapitre III

Myron Echenberg, Historical perspectives on HIV/AIDS: Lessons from South Africa and Senegal / Perspectives historiques sur le sida : leçons sud-africaines et sénégalaises

Too often HIV/AIDS is viewed as an unprecedented catastrophe. Yet lessons can be learned from earlier societal responses in both South Africa and colonial Senegal to epidemics like bubonic plague, or to coercive public health programs associated with STDs. Despite clear differences, South Africans and Senegalese resisted public health policies which blamed victims, abused power under the guise of medical exigency, and made cultural
assumptions about peoples “without knowledge”. These shared historical experiences offer a simple lesson and its corollary: health policies and programs imposed from above which do not respect subaltern voices are doomed to face strenuous resistance and likely failure. Conversely, health policies attuned to the local medical, cultural and social environment are much more likely to succeed.

Trop souvent le VIH/sida est regardé comme une catastrophe sans précédent. Pourtant des leçons peuvent être apprises de premières réponses sociales, tant en Afrique du Sud qu’au Sénégal colonial, face aux épidémies comme la peste bubonique, ou aux programmes coercitifs de santé publique liés aux maladies sexuellement transmises. En dépit de différences évidentes, les Sud-Africains et les Sénégalais ont résisté aux politiques de santé publique qui blâmaient des victimes, abusaient du pouvoir sous le prétexte de l’exigence médicale, et faisaient preuve de prétention culturelle au sujet des peuples “sans connaissance”. Ces expériences historiques partagées offrent une leçon simple et leur corollaire — les politiques sanitaires et les programmes imposés d’en haut qui ne respectent pas les voix des subalternes sont condamnées à faire face à une résistance vigoureuse et à un échec probable. Réciproquement, des politiques sanitaires adaptées à l’environnement local — médical, culturel et social — ont beaucoup plus de chance de réussir.

Chapitre IV

Benedict Carton, Historicising the Unspeakable. Legacies of Bad Death and Dangerous Sexuality in South Africa / Le silence et la honte comme objet d’histoire

In South Africa the principal mode of HIV transmission, unprotected intercourse, and the stigma that surrounds this issue have spurred historians to probe patterns of sexual socialization. But an important related theme, perceptions of mortality, has yet to receive this level of recognition. This chapter traces the topical intellectual currents propelling historians to examine the social impact of untimely death during devastating outbreaks of disease. It then compares the late nineteenth-century rinderpest epizootic to the unfolding AIDS pandemic in Zulu-speaking African communities, exploring how Western medical intervention dovetailed with indigenous penitential mourning to create a milieu of recrimination, which reflected legacies of colonial racism. Finally, the chapter traces how assertive young people, especially unmarried women, become scapegoats for spreading the sexual “pollution” said to bring about the decimation of multitudes.

En Afrique du Sud le principal mode de transmission du VIH, des rapports non protégés, et le stigma qui entoure ce sujet, ont stimulé des historiens à sonder les modèles de socialisation sexuelle. Mais un thème connexe important, celui des perceptions de la mortalité, demande encore qu’on l’identifie à ce niveau. Ce chapitre trace les courants intellectuels topiques qui poussent les historiens à examiner l’impact social de la mort intemporelle pendant les manifestations dévastatrices de la maladie. Il compare alors l’épizootie de peste bovine du XIX° siècle à celle du sida qui se déploie dans les communautés parlant le zulu, en explorant comment l’intervention médicale centrale se confronte aux rituels pénitentiels du deuil indigène, pour créer un milieu de récrimination, qui a reflété des legs du racisme colonial. En conclusion, ce chapitre retrace comment les jeunes pleins d’assurance, particulièrement les femmes célibataires, deviennent des boucs émissaires, accusés de propager la “pollution” sexuelle censée provoquer la décadence des foules.

Chapitre V

Elizabeth Colson, The Search for Healing: the AIDS Epidemic in Gwembe Valley / En quête de guérison. L’épidémie de sida dans la vallée Gwembe

How people respond to their own and others’ illnesses due to AIDS depends in part at least on timing: timing with reference to occurrence within the time span that AIDS related illnesses have been known and to other occurrences within the same support group, and a personal history of being ill or providing support to others. Responses also reflect national and family resources and the resources and social status of an individual patient. In Zambia, cabinet ministers are flown to South Africa for treatment at government expense even when death is imminent while most citizens have no access to ARVs and government health centres lack other medications. This paper uses data from the Gwembe Tonga longitudinal study to examine how the search for healing and the ability to mobilize support systems have varied over a twenty year period as Gwembe Tonga first became aware of the threat caused by the spread of HIV and then tried to deal with it. Their responses built on a recognition of increased morbidity and mortality among kin and neighbours, information campaigns about the nature of HIV, an increasing ability to diagnose symptoms as indicative of AIDS, and continuing reappraisals of both western explanations (biomedical and religious) of how HIV is transmitted and the efficacy of western and traditional medicine to treat and cure. But how people have responded has also reflected perceived obligations to support kin and the variability over time of familial and national resources, for these limit what can be done whatever one thinks should be done in a search for cure or the sustaining of those who are ill.
Comment les personnes répondent à leurs propres maladies et à celles des autres dues au sida dépend en partie au moins de synchronisations : synchronisation concernant l’occurrence de la période où des maladies liées au sida étaient connues et d’autres occurrences dans le même groupe de soutien, et une histoire personnelle d’un vécu de la maladie ou d’un appui fourni à d’autres. Les réponses reflètent également des ressources nationales et familiales, ainsi que les ressources et le statut social d’un patient individuel. En Zambie, des ministres du conseil sont partis en Afrique du Sud pour se traiter, aux frais de gouvernement, même quand la mort est imminente, alors que la plupart des citoyens n’ont aucun accès aux ARV et les centres de santé gouvernementaux manquent même des autres médicaments. Cet article utilise des données d’une étude longitudinale des Gwembe Tonga pour examiner comment la recherche de soins et la capacité de mobiliser les systèmes de soutien ont changé sur une période de vingt ans, depuis que les Gwembe Tonga ont commencé à prendre conscience de la menace causée par la diffusion du VIH, et ont alors essayé d’y faire face. Leurs réponses se sont fondées sur une reconnaissance de la morbidité et la mortalité accrues dans la famille et chez les voisins, sur les campagnes d’information au sujet de la nature du VIH, sur une capacité croissante de diagnostiquer des symptômes évoquant le sida, et sur des réévaluations continues des deux explications occidentales — biomédicale et religieuses — de la façon dont HIV est transmis et de l’efficacité de la médecine occidentale et traditionnelle pour traiter et soigner. Mais la manière dont les personnes ont répondu a aussi reflété des obligations acceptées : de soutenir des parents, ainsi que la variabilité des ressources familiales et nationales, pour autant que celles-ci peuvent limiter ce qui peut être fait par rapport à ce qu’on pense devrait être fait dans la recherche du traitement ou le soutien de ceux qui sont malades.

Part Four / Quatrième Partie — Faire face au sida / Facing the Challenge of HIV/AIDS

Chapitre VI

Gerald Oppenheimer et Ronald Bayer, Choosing Between Life and Death: Rationing of Health Care During the AIDS Epidemic in South Africa / Choisir entre la vie et la mort: le rationnement des soins de santé pendant l’épidémie du sida en Afrique du Sud

Since January 2003, the authors have been interviewing South African physicians whose careers focus, in particular, on treating people with AIDS. They include doctors in rural and urban settings, of various specialties, working within the private or public health care system. Some began treating AIDS in the early 1980s, others only recently. Many speak of the stress of caring for those with this demanding and stigmatizing disease. But most must also contend with further constraints imposed upon them by historically given factors: their health care system, relative poverty, and remnants of apartheid. A critical area, one in which all three factors converge, is that of rationing health care within a regime of material scarcity. How do AIDS doctors describe such scarcity? For them, does rationing in the face of an AIDS epidemic differ from rationing for other health problems? Has rationing changed since the end of apartheid? What do they ration and for whom? How do they negotiate with patients, families, hospitals, drug manufacturers and government to maximize resources? How do they justify rationing? How do they contend with it personally and professionally? Through what means can they distance themselves from the patients affected? How do they justify refusing effective medical interventions to people with HIV/AIDS because they have a fatal illness? How do they deal with the fact that they may be caring for some patients who can buy life-saving drugs, while others they treat, otherwise little different, must die for lack of sufficient income? Most poignantly, how do they choose among their patients those who will receive scarce resources like life-saving anti-retroviral drugs? Employing the techniques of oral history, we try to answer these questions, using the doctors’ own narratives.

Depuis le mois de janvier 2003, nous interviewons des médecins sud-africains dont les carrières se concentrent surtout sur le traitement des personnes atteintes du sida. L’enquête inclut des médecins ayant des spécialités diverses, qui travaillent dans des régions rurales et urbaines et dans des services médicaux publics et privés. Certains parmi eux ont commencé à traiter le sida dès les années 1980, d’autres plus récemment. Beaucoup d’entre eux parlent du stress éprouvé dans le traitement de ceux qui souffrent de cette maladie exigeante et stigmatisante. La plupart d’entre eux sont obligés de faire face aux contraintes qui leur sont imposées par des faits historiques : le système sanitaire du pays, la pauvreté relative et les suites de l’apartheid.

Un domaine critique où il y a une convergence de tous les trois faits est celui du rationnement des soins sanitaires au sein d’un régime de pénurie matérielle. Comment ces médecins du sida décrivent-ils pareille pénurie? Pour eux, le rationnement face au sida différe-t-il du rationnement pour sida problèmes de soin ? Le rationnement a-t-il changé depuis la fin de l’apartheid ? Qu’est-ce que l’on rationne et pour qui? Comment négocier avec les malades, leur famille, les hôpitaux, les fabricants des drogues et l’État pour maximiser les ressources ? Comment justifier le rationnement ? Comment y font-ils face professionnellement et personnellement ? Comment se distancient-ils d’eux-mêmes et des malades affectés ? Comment justifier leur refus des interventions médicales efficaces à ceux qui ont le VIH/sida parce qu’ils ont une maladie terminale ?
Comment s’y prennent-ils quand ils s’occupent des malades qui peuvent se permettre d’acheter des drogues qui sauvent la vie tandis que d’autres qu’ils traitent, autrement peu différents, sont condamnés à mourir faute d’argent ? Et le plus poignant, comment choisir entre les malades ceux qui recevront les rares ressources comme les drogues anti-rétrovirales capables de sauver la vie ? En nous servant des techniques de l’histoire orale nous essayerons de répondre à ces questions tout en employant les narratives des médecins eux-mêmes.

Chapitre VII

Paul Kocheleff, AIDS in Burundi and South Africa: a Day-To-Day Experience / Le sida au Burundi et en Afrique du Sud : le vécu au quotidien

As a medical internist, the author first came into contact with AIDS in Burundi between 1983 and 1994, then in the South African province of KwaZulu-Natal from 1996 to the present. He explains in his paper how clinicians working in these two countries and in daily contact with patients suffering from AIDS lived through the different phases of an unparalleled medical disaster. In 1984 the recurrence of unusual clinical factors suggested that AIDS was present in Burundi. This diagnosis was confirmed by a growing number of patients of Central African origin in Belgium. In 1985 a national seroprevalence survey revealed the gravity of the problem in Bujumbura with 7% of seroprevalence, whereas rural areas were almost entirely free. However, the Burundian authorities forbade the publication of the results, accusing the authors of deliberately distorting the survey. The close links between HIV and AIDS as well as the apparent African origin of the epidemic created an uneasiness which was of a racial nature. In 1989 a second seroprevalence survey, this time with a more sympathetic government, showed that epidemic had spread beyond the capital. Increasing congestion in medical departments caused by the arrival of patients in terminal stages. Health workers develop feelings of helplessness. In KwaZulu-Natal the seroprevalence rate rose from 1% in 1990 to 25% in 1996. The author witnessed the medical authorities’ reluctance to take responsibility, the negative attitude of many medical students and the stigmatisation of seropositive people in the population sometimes accompanied by acts of extreme violence. In 1997 two AIDS clinics opened in Pietermaritzburg. By 2000, the seroprevalence rate among pregnant women was 35%. Relief came in 2003 when, at long last, the South African government accepted the principle of ARV roll-out. Logistical difficulties, however, created a lot of stress among health professionals who now had to organise proper care for hundreds of thousands of potential patients.

Chapitre VIII


The proper training of health care professionals is crucial to the success of HIV/AIDS programs and interventions. This paper uses an historical analysis to highlight the changing methodologies and content of key
training organisations in Cape Town in the last decade. These shifts are discussed in light of contributing historical factors. The complex interaction between political, social, economic, and cultural factors is explored. This analysis highlights the problems and successes of training organisations and health care workers. Finally, this study provides guidelines for countries and regions with similar transmission routes, and those regions moving from the low-level, to the concentrated, to the generalised phase of HIV infection.

Une formation adéquate pour les professionnels dans le domaine des soins de santé est décisive pour le succès des programmes VIH/sida et les interventions. Cet article se sert des analyses historiques de la dernière décennie pour mettre l’accent sur les changements dans la méthodologie et le contenu des programmes des ONG les plus importantes dans la ville du Cap. Nous examinerons le développement des thèmes fondamentaux comme la lutte contre le déni, la promotion de l’engagement dans la lutte contre le sida et la mise en œuvre d’actions spécifiques. Cette analyse met l’accent sur les problèmes, les succès et les tendances futures de la lutte contre le sida. De cette manière il fournit des lignes directrices pour des pays et des régions ayant des modes de transmission similaires à ceux de l’Afrique du Sud et aussi aux pays qui progressent de la phase faible à la phase aiguë de l’infection VIH avant d’arriver à une phase généralisée.

Chapitre IX


This paper looks at the recent history of the fight against HIV/AIDS in Uganda and Senegal. It considers two success stories in the fight to confront the AIDS epidemic and suggests, in contrast to the reigning paradigm of action proposed by UNAIDS and the World Bank, that central state action has been pivotal in bringing the epidemic under control. The paper examines the nature of the political coalitions that emerged in Uganda and Senegal that formed the basis for sustained action to bring the epidemic under control in Uganda and to prevent the virus from attaining epidemic proportions in Senegal. The paper interrogates the multi-sectoral model of action currently proposed by UNAIDS and the World Bank in the context of the historical record of campaigns to fight the virus in Uganda and Senegal. It attempts to explain the basis for the much celebrated political will to engage the fight against AIDS in these two countries, considering on the one hand, the balance between action at the level of the state and in civil society, and on the other, biomedical versus socio-economic-political approaches. The paper is based on a review of documentation from domestic and international organisations involved in the campaigns, interviews with some fifty actors in the two countries, and a review of media sources from the mid-1980s.

Cet article examine l’histoire récente de la lutte contre le VIH/sida en Ouganda et au Sénégal. Il considère ces deux histoires de réussite dans la lutte pour faire face à l’épidémie du sida et suggère, en contraste avec le paradigme actuel sur l’action proposée par l’ONUSIDA et la Banque Mondiale, que l’intervention par l’État a joué un rôle central dans le contrôle de l’épidémie. L’article examine la nature des coalitions politiques qui ont servi de base à des actions qui ont permis le contrôle de l’épidémie en Ouganda et qui ont empêché que le virus atteigne des proportions épidémiques au Sénégal. L’article interroge le modèle d’action multisectorielle actuellement proposé par l’ONUSIDA et la Banque Mondiale dans le contexte des rapports des campagnes historiques pour lutter contre le virus en Ouganda et au Sénégal. Il propose des éléments de réflexion sur la volonté politique + tant célébrée pour entreprendre la lutte contre le sida dans ces deux pays, prenant en considération, d’un côté, l’équilibre entre l’action au niveau de l’État et dans la société civile et, de l’autre côté, l’approche biomédicale contre l’approche socio-économique politique. L’article se base sur une révision de la documentation provenant des organisations nationales et internationales impliquées dans les campagnes, des interviews avec une cinquantaine d’habitants des deux pays et une étude des sources médiatiques datant du milieu des années 80.

Part Five / Cinquième Partie — Debating HIV/AIDS / Débats et controverses

Chapitre X


This paper shows how Cameroon became, in the 1990s, one of the most coveted terrains for HIV/AIDS research. An unprecedented scientific interest prompted the apparition of local scientific figures and the development of new forms of cooperation. The paper tells that story. After the discovery of the first cases of AIDS in 1985 not
much research was conducted in Cameroon. Until 1988 the different research bodies of the French Department of Cooperation jointly studied the epidemic in Cameroon which was still limited in scope. At the turn of the decade the economic crisis and the establishment of the Programme national de lutte contre le sida (National AIDS Programme) radically changed the situation. Local scientists became major roleplayers. These scientists took part in the first studies of atypical viruses in Cameroon, an event of high economical, medical and scientific significance since the discovery of HIV-2 in West Africa. In 1994 the identification of a new HIV (HIV-1 group O) observed in a group of patients from Cameroon was announced. The discovery of this virus, which seemingly was of Cameroonian extraction, effectively prompted a competition between international research teams. The challenge was to collect massive amounts of blood in order to adapt the diagnostic tests to HIV-1 O and potentially to other atypical viruses. Research projects mushroomed and overlapped. They revitalised a few Cameroonian institutions. Results rewarded these efforts. In 1998 a new atypical virus, the HIV-1 group N, was isolated by a French team active in Cameroon. The phylogenetical originality of this virus and its closeness to simian viruses hinted at the possible solution of the mystery of the origins of AIDS. A new competition was launched, focussing this time on Cameroonian monkeys, not without conflicts and ethical dilemmas. More recently, with the multiplication of local and international initiatives for a wider dissemination of ARV treatment, new ways of operating seem to have appeared.


Chapitre XI

Charles Becker, Law, Ethics and AIDS in Sub-Saharan Africa. Senegal as a Case Study / Droit, éthique et sida en Afrique subsaharienne. Considérations historiques à propos du cas sénégalais

The AIDS epidemic is one of the major challenges in modern Africa. Millions of men, women and children are affected and have no access to drugs which are, nevertheless, available. Whilst scientific discoveries and past successes in the field of biomedicine have been transferred and placed at the disposition of former colonised people in order to stem the mortality rate, AIDS has been accompanied by the neglect of impoverished countries with lowered birth rates for which, eventually, causes must be sought and responsibility accepted. The epidemic poses specific problems within a context of more widespread crises and economic problems which are exacerbated by the existence of weak laws and governments. Whilst the AIDS epidemic in northern countries has provoked strong social reaction and major improvements in health systems as well as the development of ethical standpoints it has barely begun to form the basis for social and political debate in sub-Saharan Africa where legislation in the field of health is often nonexistent or inappropriate. As is the case with other health problems, the methods of assuming responsibility for AIDS (where medication is not available) and for carrying out research into the disease (done in the South by teams from the North who are often unable to apply ethical principles accepted in their home countries) must be analysed within the framework of the relations which exist between the State, health authorities and the law. This paper proposes some general reflections on the study of the slow emergence of debate on legal and ethical questions by particularly examining the case of Senegal which, elsewhere, is categorically labelled as a success story in the fight against AIDS. An historical analysis
shows that, in this case as in others, debate on these issues is rare and does not address the challenges posed by AIDS.

L’épidémie du sida constitue un des défis majeurs de l’Afrique contemporaine. Des millions d’hommes, de femmes et d’enfants sont affectés et n’ont pas accès aux médicaments pourtant disponibles : alors que les découvertes scientifiques et les succès passés de la biomédecine avaient été “transférés” et mis à la disposition des anciennes populations colonisées pour faire reculer la mortalité, on a assisté avec le sida à un abandon des pays à faibles ressources et à des régressions démographiques pour lesquelles il faudra un jour établir les causes et situer les responsabilités. L’épidémie pose des problèmes spécifiques dans un contexte de crises beaucoup plus vastes et de problèmes économiques exacerbés dans des contextes où le droit et l’État sont faibles.

Alors que l’épidémie du sida a suscité dans les pays du Nord des réactions sociales fortes ainsi que des évolutions majeures dans le domaine de la codification sanitaire et dans le développement des réflexions éthiques, elle commence à peine à faire l’objet de débats sociaux et politiques en Afrique subsaharienne, où les législations dans le domaine de la santé restent souvent inexistantes ou inappropriées. Comme pour d’autres problèmes sanitaires, les modalités de la prise en charge du sida (dans un contexte d’absence des médicaments) et de la recherche sur la maladie (menée le plus souvent dans des pays du Sud par des équipes du Nord, qui sont loin d’appliquer toujours ici les principes éthiques acceptés là-bas) demandent à être analysées dans le cadre d’une réflexion sur les relations entre l’État, la santé et le droit.

La communication proposera des réflexions générales à partir de l’étude de la lente émergence des débats sur les questions juridiques et éthiques, en examinant plus particulièrement le cas du Sénégal, cité par ailleurs, avec insistance, comme exemple d’une “success story” dans le domaine de la lutte contre le sida. Une analyse historique montre, dans ce cas comme ailleurs, que les débats sur ces questions reste encore faibles et très en deça du défi posé par le sida.

Chapitre XII

César Nkuku Khonde, A Oral History of HIV/AIDS in the Congo / L’histoire du sida au Congo selon les sources orales

Oral sources bring a decisive contribution to the history of HIV/AIDS in the Congo. While written sources cover only the period posterior to 1983, oral testimonies witness to the presence of AIDS in the early 1970s if not earlier. Migrant labour, prostitution, poverty, political conflicts determine the propagation and growth of seroprevalence in the country. The response was immediate but for a long it merely consisted of ineffective awareness campaigns. Recently a few non governmental organisations found new ways of fighting the epidemic. Unfortunately, these efforts are often impeded by various social and cultural prejudices.

Les sources orales apportent une contribution décisive à l’histoire du VIH/sida au Congo. Comme les sources écrites couvrent seulement la période postérieure à 1983, les témoignages oraux attestent la présence du sida au début des années 1970 voire plus tôt. La main-d’œuvre saisonnière, la prostitution, la pauvreté, les conflits politiques déterminent la propagation et la croissance de la séroprévalence dans le pays. La réponse a été immédiate, mais pendant longtemps, elle s’est simplement composée de campagnes inefficaces pour une prise de conscience. Récemment quelques organisations non gouvernementales ont trouvé de nouvelles voies pour combattre l’épidémie. Malheureusement, ces efforts rencontrent souvent des obstacles du fait des préjugés sociaux et culturels.

Part Six / Sixième Partie — Bibliography / Bibliographie


This bibliography only lists books, chapters of books and journal articles published in English and French. For these reasons, more attention is paid to western, central, eastern and southern Africa, than to the North and the North-East of the continent. In addition to historical studies, the choice was made to include studies in biomedical and social science which are of interest to an history of HIV/AIDS in Africa. This bibliography comprises three sections:

1. Introduction to international research on AIDS,
2. Anglophone and francophone research on HIV/AIDS in Africa,
3. Other resources for an history of HIV/AIDS in Africa, including electronic resources.
Cette bibliographie retient exclusivement les travaux publiés en français et en anglais. Pour ces raisons, davantage d’attention est portée à l’Afrique occidentale, centrale, orientale et australe qu’au nord et au nord-est du continent.

Les choix opérés pour cette bibliographie ont tenu compte non seulement des travaux d’histoire, mais aussi des études des sciences médicales, sociales et humaines qui présentent un intérêt historique, s’inspirent de la méthode historique ou fournissent des données utilisables pour l’histoire du sida en Afrique. Cette bibliographie comporte trois sections :

1. Introduction à la recherche internationale sur le sida,
2. Recherches anglophone et francophone sur le VIH/sida en Afrique,