



AIDS & Anthropology Bulletin



The Newsletter of the AIDS and Anthropology Research Group

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AIDS and Anthropology Research Group

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AIDS and Anthropology Research Bulletin

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Letter from the Chair - Elisa J. Sobo

According to the press, this year marks the 20th anniversary of AIDS. The recent spate of AIDS news coverage has given me cause to reflect back on my own involvement with 'The Virus'.

In truth, for personal reasons that I won't dwell on here, my involvement was grudging. I did everything I could to avoid professional work that had anything to do with AIDS. My eventual participation in AIDS research was fueled not by my own motivation but by a delay in funding for another project and a concomitant request for help from a physician who was trying to figure out why the female patients in a clinic he oversaw were not internalizing the HIV/AIDS education message. That small request led to a very rewarding line of primary prevention research and, eventually, to a project exploring issues related to secondary prevention.

The latter culminated in 2000 with the publication of a book that I co-wrote with medical sociologist Gill Green. I'm glad to announce that our book, *The Endangered Self: Managing the Social Risk of HIV*, has been awarded the 'Medicine & People' award here in San Diego (see page 2). I am delighted with this award, not only because it is so local, but also because it demonstrates that today, 20 years after the media first heralded its arrival, AIDS still commands attention. AIDS-related issues are universal in so many ways; it gratifies me to find that people are still interested in learning what they can about and from the pandemic. I am hopeful that the AARG can help carry this message forward as we enter a new phase of our existence.

As most of you will know, in the late 90s it became difficult for us to fill AARG offices and steering committee seats. This was due either to boredom with AIDS as a topic of research, or to a mainstreaming process by which researchers who dealt with AIDS began to organize themselves around other aspects of the topic (gender, sexuality, international health, health disparities, ethno-racial issues, etc.). Notwithstanding, AARG seems to be picking up steam and making up for lost momentum. I am looking forward to learning which members will be taking on leadership roles next year – nominations are still being solicited for the upcoming election so if you have energy to give the group do not hesitate to step forward. The health and well-being of AARG depends on you!

Most of you will by now know that the office of 'Chair Elect' has been filled by Merrill Singer. Because Singer's nomination went unchallenged, the steering committee decided that no election was necessary and Singer was unanimously appointed to the position. The Chair Elect generally serves one year as Chair Elect, then assumes the office of the Chair. The new Chair Elect will take the present Chair's place at the AAA meetings in 2001. My letter to you next Fall will contain more details on Merrill's plans for AARG as well as on the AARG events that are planned for the meetings. In the meantime, I wish you all a productive and memorable summer.



Letter from the Chair Elect - Merrill Singer

In her "Letter from the Chair," Elisa Sobo reflects on her personal involvement in the AIDS epidemic over the last two decades. Reading a draft of her comments sparked a parallel reflection of my own. It is noteworthy that there are now anthropologists – including an ever growing number with Ph.D.s – who never knew a world without AIDS. The disease has been part of their reality all through their years of growing up, the period of grappling with the decision to become an anthropologist, and the challenging period of completing the well-known test by field work (be it ethnographic, linguistic, archaeological, or biological study) that serves as our critical *rite de passage*. By contrast, I can remember a time before AIDS, a time when infectious disease really was thought to be more a part of humanity's past than its future.

My first involvement in AIDS was in 1983 (4 years after the completion of graduate school) and fell within my work as a community activist rather than as a researcher. Ronald Reagan, we are told, has absolutely no memory of those years, but I still can remember them well, including his role in delaying the public health response to the AIDS epidemic. Consequently, my first work in AIDS was helping to organize a community forum on the politics of AIDS at the local Metropolitan Community Church, one of the few venues available that did not balk at hosting a community meeting on the dreaded topic of AIDS. Fearing that all of our signs announcing the event would be torn down by those who adhered to the simple(ton) formula: AIDS = Gays = Evil, we underplayed that AIDS was the focus of the meeting. Nonetheless, 70 people showed up for the activity, mostly gay men, to hear about the failure of the Reagan administration to take AIDS seriously at a point in time when thousands of lives might have been saved. The following year we held a second forum at the Hispanic Health Council (HHC) focused on AIDS in the Puerto Rican community.

My colleagues at the HHC and I spent the next several years attempting to get CDC funding to launch AIDS prevention education based on a neighborhood leader model. We were unsuccessful. Our plan was too ambiguous, we were told. Thus it was not until 1987 that we were finally funded to do AIDS work. (However, we continued AIDS prevention education throughout this period using general community health education dollars.) Our first funded project was a community AIDS knowledge, attitudes and behaviors study directed by Jean Schensul and myself. Using a structured community survey design, we interviewed 290 individuals in Hartford. The following year we launched a follow-up survey with 400 individuals. It was evident from these KAB surveys that AIDS knowledge and risk reduction was limited by a number of key misconceptions.

In response to our research findings we developed a series of research and intervention proposals to address gaps in AIDS knowledge and to lower the level of risk in the community. From this point forward, for the last 15 years, AIDS – especially AIDS among street drug users, but also gay men, women at risk, and youth – has been the focus of a series of research and prevention projects that I have helped to develop and direct. Over this period, I have watched anthropological involvement with AIDS move from the shadows into the limelight:

Eventually this involvement waxed to phenomenal heights only to wane again to much more meager levels. The warning signs of AIDS fatigue (i.e., weariness with having to constantly hear about and worry about AIDS) began to be evident several years ago. It soon became clear that a growing number of colleagues who had devoted several years to work in the epidemic were now "moving on" to newer topics, to novel challenges, and to seemingly fresher fields. The number of AIDS-inspired sessions at AAA and SMA meetings began to shrink. The AIDS Commission of the AAA was phased out of existence. The attendance levels at AARG meetings began to drop. Within moments, it seemed, AIDS shifted from a topic of growing professional prominence in anthropology to a topic condemned to the margins of disciplinary awareness.

Fortunately, the winds of change appear to be blowing again. There are signs and signals that 20 years into the global AIDS pandemic, interest in AIDS among anthropologists is re-appearing. Of further note, the Rapid Assessment, Response,

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Letter from the Editor:

This edition of the AARG Bulletin has as its theme "Global AIDS." This topic has generated a great deal of enthusiasm among our members, as indeed it should. Our featured interview focuses on legal and ethical issues regarding the cost and distribution of anti-retrovirals to the poor in Africa by providing an overview of one researcher's (Jim Yong Kim's) trajectory from dissertation to social justice work. Carrie Fisher has provided a description of the recent UN conference. Brooke Grundfest Schoepf and Joyce Millen have both contributed abstracts on a soon-to-be published article and a soon-to-be-finished dissertation, respectfully.

Cristiana Bastos has sent a short article on the implications of social constructions of AIDS in Brazil. And William Kakwezi submitted reflections of the impact of HIV/AIDS in the Kagera region of Tanzania. We are also providing a new feature of the bulletin – a member profile of Lori Broomhall, who is now working on projects in Kenya.

One last note – our structure has changed somewhat to better represent changes that have taken place at the Hispanic Health Council. Kim Koester and Carrie Fisher have left the Council (in body if not in spirit) and are now residing in San Francisco and NYC, respectfully. While we will all continue to benefit from their contributions, I will continue to assume the primary coordination and editing role and Anna Marie Nicolaysen will continue her skillful efforts with the design and layout of the Bulletin.

A heartfelt thanks to all who contributed to this edition and please continue to send in your submissions!

In solidarity,
Janie Simmons

International AIDS Research in Anthropology: Taking a Critical Perspective on the Crisis

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Abstract

Anthropological literature on AIDS in the international arena from the 1990s shows researchers' increasing attention to linkages between local sociocultural processes that create risk of infection and the lifeworlds of suffering to the global political economy. Focus on Africa, where the heterosexual epidemic has attained catastrophic proportions, reveals some cultural particularisms but many more regularities in the social production of disease. Global inequalities of class, gender, and ethnicity are revealed, as poverty, powerlessness and stigma propel the spread of HIV. Anthropologists' witness to suffering, their concern and engagement, are potent elements in the research process, and in advocacy in national and international arenas. The combined strength of theory and practice in the field of international research on AIDS is a significant contribution to anthropology in the 21st century.

To be published in *The Annual Review of Anthropology*, 2001.

The Evolution of Vulnerability: Ethnomedicine and Social Change in the Context of HIV/AIDS among the Jola of Senegal, West Africa

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This dissertation serves two distinct purposes. First, it fills a void in the study of the Jola people of southwestern Senegal by providing the first comprehensive ethnomedical analysis of a Jola subgroup. Second, it responds to the call for deeper analytical rigor in examining the circumstances that render people vulnerable to the transmission of HIV/AIDS. The Jola people have undergone rapid and considerable social transformations in the last half-century. Drawing on historic, ethnographic and ethno-epidemiological data, the thesis traces the effects of these transformations on Jola healing, disease distribution, sexual relations, and reproductive practices. The breakdown of social control mechanisms within the family and fracturing relations between Jola elders and youth and between women and men are analyzed in relation to burgeoning local health crises. Close attention is also paid to the local effects of macro-social forces, including Senegal's structural adjustment policies, ongoing regional conflict, and economic marginalization. The thesis presents the results of an extensive 99-village study detailing local healers' beliefs and practices regarding illness etiology and changing patterns of disease severity and distribution. A study of four living generations of women and men is also presented to show interrelations between the day-to-day lives of Jola individuals, couples, and families and the changing social and cultural context of sexual relations and premarital reproduction relevant to the transmission of HIV/AIDS. The thesis concludes by arguing that efforts to change individual behavior, such as the promotion of monogamy and condom use, will continue to fail in controlling the spread of HIV/AIDS in Africa if such efforts are divorced from the political economic forces

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and Evaluation project (RARE), a community AIDS assessment and intervention project coordinated by the Surgeon General's Office on HIV/AIDS policy, is based on a rapid ethnographic assessment model, one that was developed by anthropologists (even though anthropologists interested in AIDS could not be found to coordinate the RARE effort in all the cities in which it was implemented around the country). Recently, I served on a review panel for the National Institute on Mental Health. The grants under review were written to enhance international AIDS prevention efforts. Ethnography proved to be a core methodology across the applications. Indeed, this is now a standard method in AIDS behavioral research. Unfortunately, it is quite common for behavioral AIDS grants submitted to the NIH to include ethnography in the design but no anthropologists on the staff. With AIDS grants being funded with ethnographic components, there is an increased demand to hire ethnographers. However, finding anthropologists interested in taking such positions is not always easy.

What can AARG do to help rebuild anthropological interest in AIDS, and appreciation not only of our methods and concepts but of anthropologists as researchers, applied social scientists, and public policy experts on AIDS? **The AIDS & Anthropology**

Bulletin would like to hear your ideas. We are seeking short (< 800 words) statements about how to build anthropological work and impact in AIDS. Share your ideas by sending your statements to Janie Simmons at jsimmons@hispanichealth.com, or to me at Anthro8566@Aol.Com. We will report on what we hear from you in the next newsletter.

United Nations Issues Declaration of Commitment on HIV/AIDS

By Carolyn Fisher

On June 27, following a 3-day special session, the United Nations General Assembly adopted a Declaration of Commitment on HIV/AIDS, titled “Global Crisis – Global Action.”

This Declaration of Commitment underlines the gravity of the global epidemic, stating that HIV/AIDS “constitutes a global emergency and one of the most formidable challenges to human life and dignity, as well as to the effective enjoyment of human rights, which undermines social and economic development throughout the world and affects all levels of society.”

The first section of the Declaration describes the factors relevant to understanding the global epidemic. After noting the regions most affected by the epidemic (sub-Saharan Africa, the Asia-Pacific region, the Latin America region, and the Central and Eastern European region), the UN’s prior commitments to HIV/AIDS, and the fact that the spread of the disease “will constitute a serious obstacle to the realization of the global development goals” previously adopted by the UN, the Declaration goes on to outline factors that contribute to the spread of the epidemic. These include poverty, underdevelopment, illiteracy, armed conflicts, natural disasters, stigma, silence, discrimination, denial, and lack of confidentiality. The document also describes several factors vital to reducing vulnerability to the epidemic. These include gender equality; access to medication; health and social infrastructures; access to vaccines, condoms, microbicides, lubricants, sterile injecting equipment and medical treatment, medicines and technology; the full realization of human rights, and the recognition of cultural, family, ethical and religious particularities of different countries.

The Declaration describes several approaches to countering the epidemic: prevention of infection must be the mainstay of the response, and “prevention, care, support and treatment for those infected and affected by HIV/AIDS are mutually reinforcing elements of an effective response”; prevention must be achieved by public awareness campaigns comprised of education, nutrition and health-care services; it is recognized that care, support and treatment can contribute to prevention; and it is important to strengthen national, regional and international cooperation.

Regarding barriers to treatment and prevention, the document emphasizes that “some negative economic, social, cultural, political, financial and legal factors are hampering awareness, education, prevention, care, treatment and support efforts.” In addition to mentioning non-specific factors, the Declaration states that there is a need to reduce the cost of drugs and related technology, and that “the lack of affordable pharmaceuticals and of feasible supply structures and health systems continue to hinder an effective response to HIV/AIDS in many countries, especially for the poorest people.” It is also stated that the resources devoted to fighting the epidemic “are not commensurate with the magnitude of the problem,” and that the

external debts of many developing countries have damaged their abilities to fight the epidemic.

Despite this pessimistic assessment, significant progress has been made towards containing the epidemic – at least in certain countries – through political commitment, effective use of resources, successful prevention and treatment strategies, and working in partnership with stakeholders. In addition, international humanitarian organizations and UNAIDS have made important contributions toward containing the epidemic.

The Declaration of Commitment goes on to describe eleven domains for combating the pandemic. **Leadership** at all levels of society, including government, civil society, the business community and the private sector, is essential. The United Nations is committed to facilitating plans developed at national, regional, sub-regional and global levels. **Prevention** is “the mainstay of the response.” Emphasizing the UN signatories’ commitment to reducing HIV prevalence globally by 2010, the document suggests that national plans for addressing HIV transmission should target specific spheres: the world of work; migrants and mobile workers; health care settings, as well as other vulnerable populations within particular local contexts. In addition, programs for reducing vertical transmission from mothers to their babies should be accomplished by providing information, counseling, and treatment, including anti-retroviral therapy and breast milk substitutes to pregnant women.

Care, Support and Treatment should be accomplished by strengthening health care systems and addressing “factors affecting the provision of HIV-related drugs,” such as pricing and health care systems capacity. Pharmaceutical policies and practices should be strengthened, “including those applicable to generic drugs and intellectual property regimes, in order to promote innovation and the development of domestic industries consistent with international law.” The realization of **Human Rights** is essential to the curbing of the epidemic. This includes the general human rights of all people as well as the human rights of those infected with HIV. In particular, women and girls need to be empowered to protect themselves against infection. This can only be accomplished, however, through the improvement of women’s status.

Reducing Vulnerability is another critically important domain. In addition to programs that address risky sexual behavior and injection drug use, member nations must address those factors that further increase vulnerability. These include: “underdevelopment, economic insecurity, poverty, lack of empowerment of women, lack of education, social exclusion, illiteracy, discrimination, lack of information and/or commodities for self-protection, all types of sexual exploitation of women, girls and boys, including for commercial reasons.” Groups at greatest risk to contract the disease are indicated by such factors as “the local history of the epidemic, poverty, sexual practices, drug using behavior, livelihood, institutional location, disrupted social structures and population movements

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UN Issues Declaration of Commitment on HIV/AIDS

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forced or otherwise.” (The language of this section was hotly debated – some delegates objected to explicit reference to prostitution and homosexuality. The terms “livelihood” and “sexual practices” were substituted instead.)

Member nations reiterated their commitment to addressing the issue of **Children Orphaned and Made Vulnerable by HIV/AIDS**. These measures should include: providing health services for HIV positive children; ensuring access to other needs such as food, shelter and education on an equal basis with other children; and protecting orphans from discrimination, exploitation, and violence. Addressing HIV/AIDS is one way of **Alleviating Social and Economic Impact**, since the epidemic will have grave economic consequences on all levels, from individual to community to nation.

A vital component of the international response to the pandemic is **Research and Development**. Research must be accelerated towards finding a vaccine; improving therapeutic and prevention approaches; accelerating access to technology and services; prevention of various transmission routes; and the factors which influence the epidemic. This research should occur within an environment of international cooperation. **HIV/AIDS in Conflict and Disaster Affected Regions** is of particular concern. Because conflict and disaster contribute to the spread of the disease, awareness and prevention programs should be incorporated into emergency response actions, as well as in national uniformed services and peacekeeping operations.

“The HIV/AIDS challenge cannot be met without new, additional and sustained **Resources**.” These include: expanding overall spending; increased assistance for developing countries both to provide specific assistance with HIV/AIDS services and for overall development; the cancellation of all debts of heavily indebted poor countries in return for their making commitments to poverty eradication; increased investment in HIV/AIDS research; and establishing a world-wide fund, with contributions from the public as well as the private sectors to finance the response.” Finally, the momentum must be maintained by **Follow-Up** at the national, regional, and global levels. This includes progress monitoring, evaluations, and exchange of experiences and findings.

For the full text of the Declaration of Commitment on HIV/AIDS, go to the following website: <http://www.unaids.org/> under the heading “Special Session News,” click on the words “Declaration of Commitment.” It can also be found at the following URL: <http://www.un.org/ga/aids/coverage/>

Book on Social Risks of HIV Receives Award

“The Endangered Self: Managing the Social Risks of HIV” (Green & Sobo, Routledge 2000) was awarded the “Medicine & People” award in San Diego on May 10, 2001. The book describes research conducted with HIV-positive people living in the USA and the UK. It is the second book in Routledge’s Health, Risk, and Society series.

“The Endangered Self” focuses on how the discovery of an HIV-positive status affects the individual’s sense of identity as well as his or her social relations. The experience of living with HIV is described and analyzed as the authors explore the reevaluation that people living with HIV and AIDS must make of the risks entailed by everyday social interactions, including those involving sex. The ways that people living with HIV and AIDS negotiate these interactions is examined in depth.

The authors, Gill Green and Elisa J. Sobo, are a sociologist and an anthropologist, respectively. Green is a Senior Lecturer at the Health and Social Services Institute at the University of Essex in England. Sobo is a Research Scientist at the Center for Child Health Outcomes, Children’s Hospital, San Diego, & Associate Clinical Professor at the School of Medicine, University of California San Diego.



Member Profile: Lorie Broomhall

Lorie Broomhall is a qualitative researcher in the Health Services Research Division of Family Health International in Research Triangle Park, NC. Currently she is serving as Technical Monitor on three USAID-funded ethnographic studies in Kenya dealing with HIV/STI prevention and condom promotion. One on-going study being conducted in the city of Kisumu, located on the shores of Lake Victoria in western Kenya, is investigating the cultural, organizational and interpersonal factors hindering the promotion of condoms to clients seeking diagnosis and treatment for STIs. The second project, to begin in November, will look at biases against condoms and dual protection, or the use of condoms to prevent both pregnancy and STI, among family planning service providers. Findings will be used to develop trainings and interventions to improve levels of condom distribution and quality of reproductive health counseling. A third project, currently being undertaken on coffee, tea and flower plantations in central and western Kenya, looks at female and male condom acceptability and use. This study also addresses methodological issues pertaining to the reliability and validity of self-reported condom use among project participants. Lorie also is planning a future formative study that looks at the acceptability and use of diaphragms by sex workers in Brazil. This research is the first phase of a larger study testing the acceptability of

“Delivering anti-retrovirals is not rocket science, but even if it were, we have to do it.”

Interview with Jim Yong Kim by Janie Simmons

Jim Yong Kim, M.D. Ph.D. is the former Executive Director of Partners in Health in Boston, MA. He currently serves on the Board of Trustees of Partners in Health and is Director of the Program in Infectious Disease and Social Change in the Department of Social Medicine at Harvard Medical School. Dr. Kim received both his doctorate in anthropology and his medical degree from Harvard where he now teaches and practices medicine and social justice. He also works extensively in Haiti, Peru, Russia and hopefully, Africa.

Janie: What were the concerns you dealt with in your doctoral thesis and how have these concerns become even more relevant now, or how have they changed?

Jim: Well, I was interested in the relative importance of culture as compared to class relations and economic structures in determining how health care systems work. So, I went to Korea in the late 1980s and what overwhelmed me right off the plane was the proliferation of pharmacies. They were on every corner and people could walk into a pharmacy, describe their symptoms, as if to a practicing clinician, and receive “secret prescriptions.” The pharmacist would go behind a barrier in the store and come out with little packages that were supposed to be taken once a day, twice a day, three times a day, and inside were pills and powders of all kinds. The customers were never told what was in them. But they were told, “This will help you,” after maybe a 2 minute diagnostic intervention. So, I just, I thought, wow, this is really amazing, that people have so much trust in the pharmacists. When I later found out that probably less than half of the people who dispensed these prescriptions had any real pharmacological training, I was even more amazed.

At that time Arjun Appadurai’s book, The Social Life of Things had just come out, and it really struck me. He gave us a way of doing social analysis that could move us beyond a more limited cultural or meaning-centered analysis that tended to ignore political economy and the impact of, for example, commerce on shaping health care systems. What I took from his work was that the commodities associated with health care, for example, don’t just appear out of nowhere, they’re *sold* – they have particular histories, gain or lose value over the course of their life and, of course, change meaning frequently. So instead of trying to follow families over time or individuals over time or look at culture from some other way, I asked myself what can I learn about culture and political economy by following single substances, pharmaceuticals, through their social lives?

In the thesis I looked at a particular drug which is extract of bear gallbladder and what I found was that this particular drug was not endorsed strongly by either the traditional healers nor the Western practitioners. From the perspective of the Western practitioners, this particular drug was only effective in very few disease processes, one was if the patient had very small gallstones and the other was with very obscure, rare diseases like primary biliary sclerosis. And the traditional physicians

didn’t like it either – they say, no, no, no, that is not how you do bear gallbladder. For a really effective bear gallbladder preparation you have to kill the bear, you have to take the gallbladder out, you have to dry it for 3 days, you have to mix it with these powders and you have to boil it for 24 hours. There was a whole long recipe and simply extracting one part of the bear gallbladder and then synthesizing it chemically had nothing to do with their sense of the importance of bear gallbladder in traditional medicine.

So, this particular substance wasn’t endorsed by either Western or traditional practitioners and yet for over 15 years it was the third largest selling drug in Korea. It was sold as a “liver protective medicine.” People said Koreans have problems with their livers. What that meant is that there is a lot of vertical transmission of hepatitis B in Korea. In addition, there is a lot of drinking. People do have liver problems. But the interesting thing is that this particular medicine really did nothing to help people with either hepatitis B or alcoholic cirrhosis. Still, it was sold because it utilized symbols in a very powerful way. The bear, for example, is the symbol of Korean identity. A she-bear is supposed to have given birth to the first human – who was Korean, needless to say. Also, bear gallbladder is highly regarded as a remedy in China, Japan and Korea. Actual gallbladders of bears are known to sell for as much as \$60,000.

So there was a concentration of symbols but what really made it happen was advertising. And the company that made this particular drug was a very small, obscure company before they began marketing this substance but because they hit on the right advertising strategy: by putting the “bear” in the extract rolled up in a little modernism and filial piety, it started selling like crazy. And they then changed the name of the drug company to the Great Bear Pharmaceutical Company.

Janie: That’s all they did?

Jim: That’s all they did. Through aggressive advertising they continued to maintain this particular drug very high on their list of bestsellers in Korea and they said it did all kinds of wonderful things. “If you honor your aging parents, you will buy for them this liver restorative medicine” was one of their advertising campaigns. All along there was no support for it and its use by the traditional or regular physicians, but that didn’t matter because it was sold in pharmacies. People would go to a pharmacy and say, “Ahh, I think my father’s liver is weak.” “Ahh, take this.” And at the same time pharmacists developed relationships with the company, so that if you sold a lot of the drug, you got kickbacks. And it is an expensive drug so pharmacists made quite a bit of money on it.

So my conclusion from this analysis was – well, yes, cultural ideas about health and illness are important and can certainly shape consumption patterns but these cultural ideas don’t necessarily have a connection to any of the great medical or

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“Delivering anti-retrovirals is not rocket science, but even if it were, we have to do it.”

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health traditions within Korean society. If you have enough money in your advertising budget, you can create culture and then use it to increase sales. The Great Bear Pharmaceutical company is now known as a company that really showed the rest of the Korean pharmaceutical industry the significance and importance of advertising.

And it wasn't like this was something unique to Korea. In Great Britain and the U.S. the advertising industry started with pharmaceuticals. Communication theorists have argued that the whole point of advertising is to convince people that they can fundamentally transform their experience of the world by consuming whatever it is they happen to be selling. Well, if you are going to try and train people to read and respond to advertisements appropriately, what you need to do is start with a substance that can *actually* transform their experience of the world, in this case, medicine. The first product that proved that advertising increases sales and stopping advertising decreases sales was Lydia Pinkham's Tonic which was a tonic for women that supposedly cured everything but was 17% alcohol. Raymond Williams has shown that the first advertisements in Great Britain were for certain medicinal products. So, those were my concrete ethnographic and theoretical concerns when I was writing my thesis. Powerful cultural notions of health and illness don't just come out of nowhere, out of some mystical culture-box. They can indeed be bought and sold.

Anyway, as I became more involved in tuberculosis care, in rural Haiti first, and then Peru, this idea took on a lot more urgency. It's pretty clear in looking at the drugs available for TB treatment that the primary interest of the pharmaceutical industry is not truly "protecting the health of the world." When we began to get more and more cases of multidrug-resistant TB in the mid-1990s, we needed to find alternatives to the drugs that weren't working anymore. And looking into it I learned that there haven't been any new drugs for tuberculosis for the last 30 years. Tuberculosis is still one of the top two leading infectious killers of adults, but there have been no new drugs for 30 years, because tuberculosis 30 years ago became a disease of the poor.

Well, we know that the drug industry is a profit-oriented industry; that's not news. What they do and what they won't do is very much dependent on profitability. So, then what do you do? For multi-drug resistant tuberculosis we were forced to utilize second line drugs; drugs that had been abandoned for the newer TB drugs some 30 years ago because the older drugs were more toxic and less effective, but now we are back to those because we have no other alternatives.

Now, the HIV situation is a rather different situation. There is a first-world market and therefore there is a tremendous amount of interest among the drug companies in making those drugs. What we have found out though, and very few people seem to really understand, is that with the exception of Glaxo

SmithKline none of the major research-based pharmaceutical companies that make anti-retroviral drugs have valid patents in almost any part of the developing world, especially Africa, but even in other parts of the developing world as well. They never bothered to take out patents because they didn't think that they would ever sell there.

Janie: So these patents are not universal; they are nation-based?

Jim: The way that patents work is that once you patent the product in your home country, you have exactly one year to patent it in every other country in which you want to do business. And if you don't have a valid patent in your hand within one year of the date that you patented it in your own country, you cannot go back and retroactively get a patent. So the industry has already agreed that they do not have patents, except for Glaxo SmithKline, which has patents in 37 out of 51 of the African countries, the rest have an average of one or two, mostly in South Africa; but in the rest of Africa they do not have valid patents. Therefore it is perfectly reasonable for the generic drug industry to start making anti-retrovirals to sell in Africa at much reduced prices. Unfortunately, not very many people know this and while individual companies have been forthcoming about their lack of patents, they are not broadcasting this information so the generic industry is still very worried about selling anti-retrovirals in Africa. So we are trying now to make this much more widely known and to induce the generic industry to start producing more and higher quality anti-retrovirals.

Janie: And when you say PhRMA, are you using it as shorthand for the pharmaceutical industry?

Jim: PhRMA is the Pharmaceutical Research and Manufacturers Association. That's the group that represents the research-based pharmaceutical industry.

Janie: So is that why you have been successful in doing the work that you have been doing and getting anti-retrovirals to people who need them?

Jim: Well, unfortunately, we haven't been all that successful in getting really low-cost ARV's to the people who need them. Certainly my familiarity with the drug companies has helped me to be a better analyst of the situation but actually getting the drugs in our hands for the advertised price of around \$500 a year has not been easy. For example, when the research-based pharmaceutical industry started making pledges of lower-cost drugs, I did a quick calculation in my head and compared it to the largest donation program in the history of PhRMA and realized that they couldn't possibly be serious about supplying these drugs to all who needed them. The largest donation in the history of PhRMA is by Merck, which agreed in 1987 to give a free dose of its drug Mectizan to any human being who suffers from onchocerciasis, or river blindness, caused by a parasite

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“Delivering anti-retrovirals is not rocket science, but even if it were, we have to do it.”

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common in many developing countries. In the past 15 years they have given away about 125 million dollars worth of drugs. If the drug companies were serious about these discounts for Africa it would have represented a donation or price reduction equivalent that would dwarf the Mectizan program. For example, if they provided the price reduction of around \$7,000 that they have been talking about to just 500,000 patients in Africa, that would represent a price reduction of \$3.5 billion dollars over the first year. That means that in the first year, the “donation” would be the equivalent of 28 times the value of the entire Mectizan donation and the amounts donated would only increase every year. This convinced me that, unless something dramatic had happened in the drug industry, they really couldn’t be serious about donating on that scale. I think they are under a lot of pressure to help and I think they will but there is no way that they are interested in putting their very expensive infrastructure to work on maintaining a huge drug donation program.

So the only answer I can see is really going to the generics – and the good thing is, for most drugs, it happens to be completely legal. There will clearly be problems. Glaxo SmithKline holds a lot of the cards in this struggle as they hold a lot of patents in a lot of places but they are also one of the most generous companies and I am betting that they will come through with voluntary licenses that will allow the sale of their products by generic distributors in most of Africa.

Maybe my understanding of the drug industry was helpful in formulating strategy about how to approach the drug companies. But, I think what was most helpful is my direct experience in trying to procure the drugs. With multidrug-resistant TB, you have patients who need to take up to seven different medicines, in large quantities, some of them more than once a day. Fortunately, we were able to get generous donations from Lilly and also get the generics companies involved in manufacturing. Going to the generics decreased the price of many of the so-called “second-line” treatments for drug-resistant TB by over 95% in some cases. (We just had a paper come out about this in *Science*.)

But more than some great theoretical insight I think what has made this possible is the practical experience, the fact that my coworkers and I at Partners in Health actually participate in the management of programs on the ground. So instead of performing a longitudinal study of what pharmaceutical companies have done and what they’ve not done and doing a discourse analysis of what they say and what they do etc., I have the actual experience of trying to get drugs for folks who need them. And when you do that it truly does refine your perspective. If I didn’t have this other perspective from anthropology about the nature of the industry and the history of the industry, I think certainly my overall understanding of the situation would have been more limited but I think it is the practical experience that has been the most helpful, probably more helpful than my academic training. But without question,

training in anthropology prepares you to deal with language and words and culture and perceptions in a way that few other disciplines do, I think.

Janie: Now what has been covered in the media shows a lot of people fighting against the way things have been in terms of the pharmaceutical industry. Do you think that the representations you have read about in the media are accurate or is there something missing?

Jim: In the area of HIV or in general?

Janie: Yes, in the area of HIV.

Jim: I think what you hear about in the media is that the Indian generic company CIPLA is coming in and selling at low prices and the research-based pharmaceutical industry is ready to lower their prices dramatically. I think the pronouncements are all great, but again if you again look again at the Mectizan donation, after Roy Vagelos, who was the CEO of Merck at that time, said, “Free Ivermectin for all human beings suffering from onchocerciasis,” it took at least three or four years before they even began distributing the drug. And it took six or seven before the program went to scale. I’m sure the pharmaceutical industry is expecting this kind of a delay with antiretrovirals. And the UN agencies are playing right into it by spending all their time fighting over who controls the money as opposed to getting to the business of procuring the drugs and getting programs up and running. This is the idea I have been trying to push with certain people in Congress – let’s take the next steps.

As I mentioned, when we tried to get these drugs for Haiti, we made at least 100 phone calls to each of the drug companies and then the final price we got for a one-year regimen was not \$500; it was closer to \$2,000. So that was cheaper; that was a discount, clearly, but not nearly to the extent that we thought it would be and also, it took us, again, more than 100 phone calls to each of the companies. Now what does that mean really? That means that the companies made the pledges but they are not expecting to have to move large quantities of drugs for some time because if they were the infrastructure would already have been set up. We wouldn’t have had to bounce back and forth between dozens of different people at those companies in order to get a straight answer about where and how to actually get the drugs. And Haiti is a place where they had already been selling the drugs. They had distribution mechanisms already set up in those places but it took that long to just get a price of \$2000: which is not that great.

And if you look at the generic industry, there are generic producers but not nearly of the quantity and quality that are necessary even to supply the pilot projects. We know this because we have dealt with generic procurement agents like the International Dispensary Association in Amsterdam. We work with them on many different issues and so we just asked “what’s the story?” And they said, “Well, a lot of people are interested

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“Delivering anti-retrovirals is not rocket science, but even if it were, we have to do it.”

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in this but the number of reputable pharmaceutical manufacturers in India and China who are making these drugs is very limited and thus the overall quantity available is also very limited right now.” So it just doesn’t exist and in our experience once the generic industry starts getting interested, it will take a year and a half to two years before they can make the drugs in any quantity at all. So, no commitment has really been made to begin ARV manufacturing within the generic pharmaceutical industry, and even when they do commit, delivery will still be a year and a half to two years away.

That’s why we are screaming, “let’s start now, let’s make a pronouncement, let’s do something right now.” Recently, a group of people including PIH has been asked by a couple of people in Congress to write a White Paper outlining a plan for a Global AIDS Drug Store. It will be very simple. It would start by saying, O.K., here’s where the patents exist and here’s where they don’t exist. Therefore, in all the places where they don’t exist, generic manufacturers should be able to sell their drugs. We will also work to get voluntary licenses from firms that do hold licenses and if needed, other completely legal measures such as compulsory licensing and parallel importing will be implemented. Meanwhile procurement agents who will do the quality control will also ensure that the drugs go directly to the countries and programs most afflicted. But, the countries and programs that apply for free or very low cost drugs won’t get them unless they have a high level of political commitment to prevention and all other aspects of a comprehensive HIV care, prevention and treatment program. If they need technical or other assistance to build a comprehensive program, the Drug Store should ensure that they get it right away so that they can qualify for the drugs very quickly.

To me that’s the perfect solution. You increase the number of drugs by nurturing the generics industry and procuring high-quality drugs in large quantities, but you only give those drugs for free to countries and organizations who are willing to do all the other necessary steps in HIV care. The worst possible thing would be for some government to try to win some public relations victory by sprinkling these drugs around and then using them in ways that are clinically and epidemiologically dangerous. You don’t want irrational use; that’s clearly not what anyone wants but you also want to make these things work faster and I think until someone says, “Yes, it’s O.K. generics should go to places where there are no patents and we need voluntary licenses on the patented drugs” everything is going to be stalled and right now everything is stalled. So that’s what we are working on. Unfortunately, the reality of the situation is that there have been a lot of pledges and a lot of hot talk but nothing really happening. Not a single penny has yet been spent from the bilaterals (the government aid programs) or multilaterals like the World Bank to a patient for treatment as far as I know.

Janie: And in terms of this UN declaration that just come out, will that have any relevance for furthering this process?

Jim: I don’t know. I think people are still very scared about

treatment. They talk about “infrastructure” as if it’s good will, or love, something that everyone is very quick to stand up and decry the absence of. Well, obviously we don’t have enough good will or love in the world. But because it’s so difficult to define love or good will, we are freed of any responsibility to build it or increase it. Infrastructure, though, is something very specific. We treat patients with multi-drug resistant TB in Haiti and the slums of Lima and most multi-drug resistant TB treatment is much more difficult than anti-retroviral therapy. The kind of infrastructure that is necessary is not nearly as complicated as one might think. And people seem to be so scared of starting a project and “failing”. But I don’t think that’s where we should be. We should be immediately initiating 50 different pilot projects at once and assume that many of them are going to fail, if not most, and that as these projects fail, we’ll learn some important things about how to deliver the anti-retrovirals.

Actually, I think the question is not about whether or not there is infrastructure. The question is what do we want to do about the 30 million poor people who are already infected. That’s the only question that is important. And once you say, we can’t let them die; we can’t just let them die when we have treatments available, then we’ll figure out what to do. Right now in Haiti, we are providing anti-retroviral therapy with extremely little extra expenditures on top of our TB control program. With a few extra days of training for the health care workers who administer our TB treatment program, we can deliver HIV treatment. And it is working extraordinarily well. We brought blood samples back from our first 11 patients and 9 of those 11 had undetectable viral loads. This is an amazing outcome.

So the only question is deciding whether we really want to do it or not. At these conferences you hear a lot along the lines of, “You can’t separate treatment from prevention but you know there is no infrastructure for treatment.” Well, I disagree. I think Malawi and Kenya and Tanzania and Botswana all have great TB programs and if you think hard and work hard you can modify and expand those programs to deliver anti-retrovirals. Everyone says, “Oh, but it’s so hard”, but we are talking about spending trillions of dollars on a missile defense system that we know won’t work against an enemy that we have yet to define! And people are so scared about possibly failing in the first 50 cases of trying to deliver anti-retrovirals! I sometimes think that people have lost their minds.

Our generation is going to be defined by what we do about HIV. The excuses that we are coming up with, “no infrastructure...” “oh gee, too many pills...” “oh you know, they can’t tell time,” those excuses are going to look as bad as notions of preserving Aryan purity in 10 - 15 years. I guarantee it. What I always say is, delivering anti-retrovirals is not rocket science, but even if it were, we’d have to do it. We’re talking about whole societies that are going to be devoid of adults – it’s only going to be senior citizens and children. What are we

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Behavior as social variable and social variables as behavior: lessons from the AIDS epidemic¹

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In one of the earliest attempts to frame the global dimensions of AIDS, the World Health Organization (WHO) represented the state of the epidemic in a three-pattern world map.² Pattern I covered Western Europe and the Americas, and corresponded to a high incidence of AIDS cases among male homosexuals, intravenous drug users, and blood recipients. Pattern II covered most of Africa, and was described as a type of AIDS that affected men and women alike. Pattern III covered Eastern Europe and Asia and equated to low or no notified AIDS cases. In sum, there was a pattern I related gay men and blood, and a pattern II related to heterosexuals.

A few years later the same leading author criticized the model and suggested accounting for a larger number of patterns in worldwide AIDS.³ However, the idea of a dual epidemic remained. Using data from research in Brazil, I will discuss here some of the implications of that formulation, and explore how the study of AIDS helps understanding some of the epistemic, practical and political aspects of the relationship between epidemiology and anthropology.

One of the implications of suggesting a pattern I / pattern II model for AIDS was that it led to the understanding of a two-in-one epidemic, with two overlapping phenomena. It remained unclear whether the two “patterns” of AIDS transmission also corresponded to different patterns of presentation of symptoms, or if there might be two distinct infectious agents, or two varieties of the same one. Even though the article did not explicitly refer to two different epidemics, there was an emphasis on a dual model, one that roughly duplicated the macro-geographical contrast in patterns of development. This emphasis went together with an absence of questions about the social and medical variables that might explain why the disease was transmitted differently in Africa and in Europe/North America.

This is not a mere academic issue. The dual frame for AIDS remained in the public imagination and had important consequences everywhere. In Brazil, for instance, there was the notion that there was an **American AIDS** and an **African AIDS**, as in an opposition between developed and underdeveloped styles of disease. Brazil is often described as a First World/Third World combination: urban middle and upper classes suffer the ills of “development,” like heart disease and cancer, and the masses suffer from the infectious diseases of underdevelopment.” When AIDS arrived, though, it was seen as a disease of development. Most of the early notified cases were among middle or upper class urban gay men or blood recipients. The media helped shaping the notion that AIDS was a “First World disease,” or *doença de rico*, and Brazilian AIDS stood as a sign that the country shared the problems of the U.S. and Europe – not those of Africa.

Yet we know now a different story. There were probably early cases of AIDS among women and others that simply did not show up as AIDS.⁴ Their symptoms were hidden behind the

many faces of infectious disease and poverty, mixed with, respiratory disease, emaciation and uncontrollable infectious processes. Only the cases of AIDS-like symptoms that surfaced within the loop of the relatively privileged, those outside the world of generic infectious diseases, those that infected members of the “first world within,” became known as AIDS. As soon as some cases of AIDS among women became known to the public, the media fomented the notion that Brazilian AIDS was becoming “Africanized.” Becoming “heterosexual,” to borrow the initial categories used to frame AIDS patterns, AIDS in Brazil was associated with the stereotypes of poverty and blackness. Public health officers and AIDS doctors had to work hard to argue against the media stereotypes. But they often worked at the same ideological level as the media, arguing that AIDS in Brazil was pattern I, not “African”, instead of questioning the entire dual pattern. They did not go far into discussing the social variables associated with disease distribution, in spite of the fact that there was a local tradition of social epidemiology and a vibrant field of research specializing in infectious diseases. Instead, both specialists and the media remained tied to pseudo-social groups defined by individual behavior.

More than ten years after the publication of “The International Epidemiology of AIDS”, many things have been revised. We know now how to better frame the diversity of variables involved in the AIDS epidemic in Africa and what lies under the vague and behavior-inspired label of “heterosexual.” They are overlapping medical and social variables; they refer to parallel “epidemics” of multiple infections, poverty, malnutrition, forced migration, reckless urbanization, forced militarization, low- and high-impact war, and many forms of violence regarding gender interactions, sex, age groups, family structures, immediate survival, and the exercise of state control. A few short years after the publication of his 1988 article, Jonathan Mann addressed the World AIDS Conference, showing the social, political and economic dimensions of AIDS as best illustrated in Africa, and how public health campaigns had to account for gender, age, class, power, empowerment, dependency.

AIDS in Africa, we may add, also highlights the remaining structures of asymmetry and disenfranchisement inherited from a painful historical process of colonization and decolonization throughout the world. In this sense, AIDS in Africa or, for that matter, among the disenfranchised populations, reminds us of the wider macro-political and economic processes that produce and maintain underdevelopment and poverty. The richness of analysis that the incidence of AIDS in Africa provides was certainly obscured by the temporary use of the category “pattern II,” or heterosexual AIDS, to describe the local forms of the epidemic.

It is my argument that this process of “simplification” of the subject directly stems out of an epistemic feature of the discipline of epidemiology. This feature corresponds to equating behavior to social variables and from there to define social

groups. By defining social groups after individual behavior, or collectively repeated individual behavior, epidemiology appears as a social discipline, as if it was addressing, in fact, social variables. In the meantime, the actual social variables involved in the incidence of disease may simply be hiding behind the pseudo-categories defined by behavior. What is needed, I suggest, is for anthropologists and other social scientists to be aware of the process and complete the models proposed by epidemiologists by bringing in their own analyses and findings, as opposed to following uncritically what epidemiologists may have suggested.

We may ask at this point why medical anthropologists involved in AIDS work were not able to bring in a more critical perception of the epidemic, and, instead, have followed epidemiologists' models based on fragile social categories that consisted mostly of treating repeated individual behaviors as social variables. In the same line we may ask why Brazilian social epidemiologists, familiar with handling the actual social variables associated with disease distribution, did not contribute at once to a more critical understanding of the epidemic patterns in Brazil and, instead, let the public indulge in debates of whether AIDS in Brazil was homosexual, heterosexual, American, or African.

Maybe the first answer is that research is slow and the first responses to AIDS were necessarily incomplete and imperfect, using weak tools of social analysis, and that things improved later. But I suggest that we should also investigate the political hierarchies that rule the relationships between branches of knowledge, between disciplines, and between disciplinary schools working closer or more removed from the centers of decision. In this case, evidence shows that medical categories were at the basis of the social categories defined to understand the epidemiology of AIDS, and that epidemiological knowledge, while looking like social knowledge, behaves as subordinate to medical knowledge. That anthropology and the social sciences had their own means to critically reframe the social understanding of the epidemiology of AIDS – including the understanding of why it varied in Africa and in the Americas, or why it varied within Brazil – was not considered at first. The same suggestion goes for the fact that Brazilian social epidemiology could hardly contribute to a critical re-framing of the initial dual model for AIDS: here was a branch of knowledge that was dually marginalized, both in the hierarchy of disciplines and in the hierarchy of where one is situated to produce legitimate knowledge. Like their fellow infectious disease specialists in Brazil, the international package of knowledge about AIDS was much too complete and fast, coming from centers like WHO and the CDC, and ready to be used in an emergency, even if epistemologically insufficient and unsatisfying for social scientists.

¹ An earlier version of this paper was delivered at the session EPIDEMIOLOGY, POPULATIONS AND SCIENCE: EXPOSING THE GOVERNANCE OF DISEASE, 98th meetings of American Anthropological Association, San Francisco, November 15-19, 2000. I am thankful to the organizers of the panel and to all the people that had previously

helped me with the research at the City University of New York and at the State University of Rio de Janeiro. I also thank the Wenner-Gren Foundation for Anthropological Research, the Social Science Institute and the Luso-American Foundation for Development for financial assistance in different moments of the project.

²Mann, Jonathan, James Chin, Peter Piot, and Thomas Quinn, The International Epidemiology of AIDS, *Scientific American* 259(4):82-89

³ Mann, Jonathan, Daniel Tarantola, and Thomas Netter, eds.

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doing sitting around and waiting for that to happen?

In terms of disciplinary training, well, sure, anthropology is helpful every day, but I think that our closest allies are not necessarily people who have anthropological training. Our allies are people who feel that this is a moral imperative and that social justice in this case, social justice and solidarity, are our most important values.

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The HIV/AIDS Epidemic in the Kagera Region of Tanzania: Some Considerations with Regard to the Socio-economic Situation

By William Kakwezi
Bukwali Dispensary, P.O. Box 1288 Bukoba, Tanzania

Historically the first 3 HIV/AIDS patients were reported in the Kagera region on the West side of Lake Victoria, bordering Uganda, Rwanda and Burundi. Bukwali Health Post is right at the border with Uganda. It is here where HIV/AIDS entered first. Trading with Uganda took place here, at Lukunya, which brought many young people from the Kagera region and Uganda. Promiscuity and prostitution were well established in the area. This was in 1983. The immediate result was the devastation of the nearby area known as Kashenye, in which Bukwali is situated. This affected mainly the most productive and reproductive group, those aged 15 to 45 years. Later, HIV spread to surrounding wards, even though it seemed as if it were abating, having wiped out the most active segments of the population, but also leaving behind lots of orphans and widows. It was dramatic as one looked at the graves everywhere and the standing motorcycles acquired from the flourishing trade. The orphans were attended to by various NGOs chiefly Partage, and some have survived beyond primary school. Unfortunately due to barriers to secondary schooling, some of these young girls have become pregnant.

Problems now:

The area is far from the regional hospital some 55 kilometers from Bukoba, where testing and treatment are available. This is one of the causes affecting the victims of HIV who languish in the villages. Of course there is the poverty factor. The only cash crop in this region is coffee, and this is subject to the world market. All in all the price fetched is always low. Subsistence is low and the people live below the poverty line. Tanzania, as is well known, is one of the least developed countries. The cost of living is high; the cost of medicine is prohibitive. Biomedical treatment for HIV/AIDS is unaffordable.

Regarding epidemiology, we go by data reported in hospitals. Though Tanzania has one of the best established grassroots systems, based on the ten cell units, we have as yet not been able to utilize fully the aims of this structure. Consequently, there are many deaths from various causes including HIV/AIDS going unrecorded. As I mentioned earlier, laboratories with facilities for testing victims are scarce and far removed from rural areas. The hospital services, as well as resources, are overstretched. Even drugs for managing STDs other than AIDS are not easily accessible. The cost of drugs as well as expensive hospitalization, have caused some to resort to traditional healing facilities. We all know the indigenous healers have become scarce too, and those existing may be lacking in healing techniques. Attempts are made at the moment to form traditional healers associations in order to bridge gaps between the conventional medical personnel and indigenous healers. The latter claim they can treat HIV/AIDS by using herbs and barks.

Other aspects of the epidemic are the effects on the families. Apart from the orphans, the traditional families, do hope to invest in their futures by educating the children. With the strike of AIDS, one can easily realize the misery the families have to suffer. The nation has suffered too, by losing the skills and the quality of leadership. We should not forget the plight of the elderly. Traditionally families in African communities did have the capacity for absorbing and accommodating the elderly, orphans and the mentally ill. Hence the extended family system. This has been eroded for the most part. We are bound to see an increase in psychological problems in the communities.

To conclude, I have briefly sketched some of the areas where the HIV/AIDS scourge has and is continuing to make an impact. Both education and treatment are still limited. Developing poor countries, as is well known, need help and all kinds of support, in kind and in dollars from the rich developed nations. It is true such brethren have been doing so from the start, as we can see the numerous organizations in the field. But this help has to be magnified in order to curb the spreading epidemic. Fatalism has established itself among the young and this is disastrous.



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