THE ANTHROPOLOGY OF AIDS

C. David Pitt
Co Chair Commission on AIDS, International Union of Anthropological and Ethnological Sciences.

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Contents

Summary

This chapter provides an indicative archive of different approaches from anthropology, broadly defined, to the HIV/AIDS pandemic. Although there has been some interest from biological anthropologists in the history and origins of the pandemic, including the relationships between the virus and the syndrome, the major thrust of research and action has been from social/cultural anthropologists and ethnographers concerned with cross cultural constructions of disease and a critique of biomedical models and praxis. There has also been an advocacy of more use of cultural elements in all health programs and more widely in education and sustainable development. Much attention has focused on two main modes of transmission of HIV in which there are risky behaviors, ie sexual contacts and injecting drug use. Important too has been the politico-economic (neo colonial) context, particularly relationships to power and poverty, the lowly position of women often in situations of war and socio - economic turmoil. Anthropological criticism has been most concerned to combat stereotypes, prejudices and mythologies concerning "those living with AIDS", (especially where infection is most prevalent in sub Saharan Africa) including misinformed assumptions about tradition, magic and sexuality i*nter alia*. The anthropological narrative has argued that some quantitative epidemiology and much health policy has hindered rather than helped the understanding, prevention and control of the pandemic, whilst local, culturally appropriate "health and development from below " movements are more often successful than officially recognized. Increasingly anthropologists of AIDS are working in applied settings especially in international agencies providing cross cultural perspectives and advocacy, promoting qualitative methodologies and contributing to major planning exercises such as the Millennium Development Goals.

1. Introduction

The purpose of this chapter is to present an indicative archive illustrating past and present research and action in the anthropology/ethnography of HIV/AIDS (and from allied social sciences) as well as future perspectives. HIV/AIDS has been called the first global epidemic, a series of epidemics, or pandemic, where definitions and policies have been the product of international organizations as well as the biomedical professions. Anthropology is broadly defined to cover all those disciplines, however labeled, which derive much of their data from close ethnographic observation of structure, culture and mentalities at the grass roots (or from intensive historical ethnological study), often in small scale societies, using models which reflect local mentalities and customs focusing not only on the big political/economic/ecological events but also on what Chauvier calls the " la vie ordinaire". A main contribution from the anthropology of HIV/AIDS especially, has been to present alternative cross cultural perspectives especially from developing countries, notably in sub Saharan Africa where there is most infection. Strongly applied, anthropology has striven to make health and sustainable development programs more effective, "from below" where communities and the oppressed within them, notably women, should be empowered to become more self reliant.

The focus of anthropology has been then on "other " cultures, communities and behaviors, often characterized (mainly by outsiders) as exotic (ie non Western), erotic (e.g. derived from alternative sexual identities and practices) or deviant(e.g. based on drug/substance abuse).Culture includes " ways of life, representations of health and disease, perceptions of life and death, sexual norms and practices, power and gender relations, family structures, languages and means of communications -- art and creativity" (UNESCO 1982).In the plural, cultures are distinct social entities which constitute an alternative cartography to a world based on ~ 200, mostly multicultural, nation states which may however attempt to impose a single national culture, or in the health field, apply international norms derived from the dominant biomedical sciences strongly influenced by especially American pharmaceutical industries.

UNESCO counts more than 6000 cultures based on languages, many disappearing, whilst others have doubled this figure and have added a very wide range of what are often called sub (neo) cultures which rapidly form not least in the context of the HIV/AIDS pandemic so prevalent in migrant communities, as well as more amorphous, and often evanescent, (including virtual) networks, a process somewhat like the spread of the disease. Other social factors e.g. religion or presumed ethnicity may make cultures distinct structurally, whilst oppositions are common (counter cultures), producing much conflict. Where there is less multiculturalism there are still marked behavioral differences in relation to the pandemic based on space (regions, localities e.g. China), time (e.g. generations) or structure (e.g. class in America and Europe) or gender. Outsiders who seek to prevent and control the pandemic are also a subculture(academic, scientific, health policy etc), whilst anthropology, which Eric Wolf called the most humanistic of sciences and the most scientific of humanities, tends to straddle the structure as well as championing bottom up processes from the "other " cultures. An essential task is to improve cross cultural communication, horizontally as well vertically top down and bottom up.

The popular stance has meant that anthropology has often been critical of perceived top down tendencies whether in the biomedical professions, government policies or capitalist business practices often seeing postcolonial globalization continuing to be unjust and inequitable if not abusive. The late Jonathan Mann (who brought several anthropologists into the WHO programs on HIV/ AIDS) talked of a third, and even more serious epidemic in addition to the virus and the syndrome, that of fear where and when human rights were ignored or flouted, where populations panicked and phobias were ubiquitous, and stigma was an important obstacle to treatment.

The anthropology of HIV/AIDS had its roots in several strands from Enlightenment humanistic and humanitarian ethics in which, in the traditions of Virchow and Durkheim, the disease was seen as social or more precisely of society, ideas that were continued in the "practical anthropology" of Malinowski in colonial settings and by his student, the doyen of contemporary applied anthropologists Fei, working in, and from China. Levi Strauss has argued that this humanism passed through aristocratic and bourgeois directed stages to populist, universalistic ethics (such as the international Health etc for All programs), changing to present efforts to find a reconciliation between humans and a nature which constantly and ultimately controls. The anthropological models of HIV/ AIDS were less derived from Pasteurian germ or immunology theory, which relied often on a sometimes statistically suspect quantitative epidemiology (and some confusion of cause and effect) and which had largely failed to explain or contain the pandemic, or provide a cure or vaccine. Rather there emerged in anthropology alternative qualitative models such as those derived from the structuralist "mythologies" of Levi Strauss, and the power theses of Foucault (himself a victim of AIDS) who argued that sickness is a degraded and oppressed status in itself, and bolstered other discriminations e.g. as demonstrated by one of his students Rubin in relation to gender and sexual subcultures. These models also established the worth and equality of the "other", cultures and subcultures so often summarily dismissed by too often ethnocentric, nationalistic, western institutions dominated by so called "tribalist" " Africanist " "orientalist" "machismo" etc ideas, which were not a solid or sympathetic base for effective health programs.

In an age of globalization anthropology also added new dimensions to the somewhat static, colonial cartography of a multicultural, tribal, world by looking at more fluid phenomena. These included both newly emergent, if transient, sub cultures but also egocentric networks which often lie under the radar, often tabooed e.g. for their assumed "deviant" sexualities, or simply "invisible" whether in the heart of a Conradian rural darkness, or outside the door in the ubiquitous urban slums, or in the concentration of camps housing so many refugees displaced by continuous war, violence and the degradation of nature and society. Anthropologists were less quick however to study the implications of the telecommunications revolution, and the virtual world of the internet, where even if the great majority of the world's population is now on line, and young people are major users, there remains "digital divides".

Although HIV/AIDS is largely a poor third world problem (even if first noticed in America) there are growing disparities too in the rich world, and the former socialist societies " in transition ", sometimes called an excluded fourth world (the term is also

applied to indigenous peoples), ravaged by crime, prostitution and drugs, emanating from outside which helped potentially spread the disease to all classes.

To help in all situations anthropology has made the case arguing for not only the imperative of top/ trickledown "aid for AIDS", for more health and welfare, but also to recognize the many traditional and/or grass roots organizations, often unrecognized success stories which should be built on. A model described by Staugaard and his colleagues is Ipelegeng (do it yourself) in Botswana (the country which even if relatively wealthy has the highest rate of HIV in the world) where ideas and actions "bubble up", adapt coexist, cooperate, collaborate and cope, building on local initiatives, traditions (albeit sometimes syncretic), the strength of women, widespread will power and the potential of a mix of placebo and phytotherapy etc.

Methodologically the anthropology of AIDS has continued to use classic intimate, empirical, participant observation, rejecting the "quick and dirty" questionnaires of much quantitative epidemiology, even if such field work became ever more difficult and dangerous. Added to this, heavily influenced by Triste Tropiques (Levi Strauss) were literary (Proustian), rather than literal interpretations, even irrationalistic (Elster). Adieu au voyage then to use Debaene's phrase. More and more insiders and local people became analysts instead of simply being interpreters or informants, and an important AIDS fiction and poetry has emerged particularly from the American gay community rather than from Africans or Afro Americans who apparently did not want to be associated with what some saw as a gay white disease. Many social scientists as well as health professionals and notably journalists used ethnographic techniques whether or not labeled as anthropology, which remained, largely because of its colonial connotations, a politically incorrect word in some places. Indeed the corpus of knowledge was catholic in scope drawing not only, on portmanteau anthropology itself (social, cultural, physical/biological etc) but also the tripartite Kagan cultures (natural /social sciences and humanities) and significantly popular proverbs and wisdom, whether or not of crowds, notably and increasingly in the wikiworld and google globalism on the Internet. In explanation and application the focus expanded from the synchronic world of a year or so in the field to historical dimensions (and a futurology useful for planning), drawing e.g. on the inspiration of Evans Pritchard. Often employed in health and development agencies, anthropologists also turned their nano techniques on those who dispensed aid and advice. Galtung talked of United Nations "tribes" dominated by rituals as much as rationality, even Turner said witchcraft, part then of the problem rather than the solution.

The concern was not only with observation of behavior but the mental constructions that preceded and followed from it. Thus much attention was paid to language following Wittgenstein, to words as much as things to use Gellner's phrase, (e.g. Higgins), discourse, dialogue, metaphors (of decay e.g. Sontag) or even apocalypse (Palmer). These notions in the mind (noosphere) influenced both those living with AIDS (as patients were called in the official language) and those who cared for them adding to the climate of fear that Mann had talked about even though metaphor (and dialogue) in the anthropological literature (e.g. Beck) were seen to act also as mediating mechanisms in the healing process along with proverbial traditional wisdom and beliefs in the magic

and supernatural e.g. in the book" Man Cures, God Heals" by Appaiah Kubi, who advised WHO on the Akan of Ghana.

2. History

Anthropologists were amongst the first to comment on the arrival of AIDS when it was classified in 1981 and when the presumed causal agent HIV was identified in 1983. The first victims in the USA cut down by a devastating collapse of the body's immune system accompanied by rare and bizarre opportunistic co-infections like Karposi's sarcoma were homosexuals/drug takers in the gay community part of an innovative postmodern so called "queer" movement which challenged all orthodoxies and which had succeeded the narrower hedonistic largely heterosexual libertarian philosophies of the sixties and seventies. The heterosexual HIV/AIDS phase particularly in sub Saharan Africa, (in 2007 21 out of 33 million world wide, ~ 25 million dying from the outset of the pandemic) also quickly attracted the attention of the anthropologists who had from colonial times worked extensively in the field there. Some ethnological research pushed back the dates when HIV/ AIDS arrived, in one case to the Middle Ages when a survey of portraits supposedly revealed the black spots of Karposi's Sarcoma in a time when an even more devastating plague, the Black Death, carried off far more than HIV/AIDS. Although medieval immune responses were undoubtedly low because of bad weather (the Little Ice Age), poor harvests, constant (e.g. the 100 year) wars, cruel crusades, economic depression (land prices did not rise between the 11th and 17th centuries) in times of personal sadness(the Middle Ages were called the vale of tears), the arrival of the HIV/ AIDS epidemic was somewhat different. The present is a period of global warming, economic boom and bubble if occasional bust, relative peace or cold war (even if more have been killed since World War 2 than in it), enough food even if some become obese whilst others starve, more aspiration and legislation for human rights even if there is widespread abuse. HIV is a slow (lenti) virus possibly present for millions of year, with a wasting syndrome, controllable by ARVs even if many cannot obtain access to them, where the human is the vector through limited contact of body fluids, different then from the sudden Black Death due to the bubonic bacillus transmitted by rats and fleas though droplet infection was important in the pneumonic phase. It is not known if this pneumonia was the opportunistic Pneumocystis carinii typical of HIV/AIDS which was discovered as early as 1909 amongst malnourished children

Mann estimated that there may have been as many as 100,000 cases of HIV/ AIDS before 1980. HIV may have originated amongst primates in Africa in the late 19th century as SIV (Simian Immnuodeficieny Virus), probably amongst chimpanzees in the rain forests of SE Cameroon and in the Democratic Republic of Congo who although carriers had evolved a resistance. In the "hunter" theory the virus jumped to the human population when bush meat was cruelly and unhygienically butchered sometimes involving rare and endangered species. Very little is known however on how the disease was transmitted before 1980, though wasting anorexias (slims) and PUOs (Pyrexias of unknown origin) had been widely and long noticed in Africa. The earliest possible cases identified by symptoms date from the 1950s including several sailors(though not all had visited Africa) and the tissue analysis at Tulane University School of Medicine in 1987 of Robert R., an Afro American who died in 1969. Some blamed the arrival of HIV in

the Americas on a Haitian migrant who had worked in the Congo though Farmer argues convincingly that this accusation has more to do with prejudice than hard evidence. Similarly the idea that a promiscuous Canadian Flight attendant, Patient O, brought in the virus owes more to the journalist Randy Shilts' account (and the Hollywood film) " And the Band Played On " not least since the disease was well established before Patient O, whist his sexual prowess was probably more bragadaccio than bordelo. At first the condition was called GRID (Gay Related Immune Deficiency) but this was quickly changed (1982) when it was realized that up to half of cases were not gay but hemophiliacs, intravenous drug users or heterosexuals. The widespread image of promiscuity e.g. in Africa as we shall see is arguably mainly myth, based on misconception and prejudice if not manufactured in the media.

There are many popular theories on the origins of the virus which the biomedical profession usually discounts. Many local people in Africa believe in insect vectors, especially as there is much propaganda to avoid being bitten by e.g. mosquitoes in malaria control. Others who are deeply suspicious of the West and the Americans in particular, regard AIDS as a designer disease concocted by the CIA as part of a eugenics program or germ warfare, escaped or liberated from a laboratory. There is widespread feeling too in Africa that vaccinations and injections are, whether or not intended, harmful and there is indeed much data on the adverse consequences of dirty needles and syringes. Hooper has blamed misguided polio vaccinations for the epidemic itself whilst Weinstein argues that stopping smallpox vaccination was a cause of HIV infection. Whether or not these explanations of origins are true the fact they are widely disseminated, not least now on the web, and widely believed, is very important. Conspiracy theories indicate a wide social distance between health authorities and communities which certainly impedes communication, effective prevention and control. Many locally blame poverty and continuing colonial tendencies for sickness generally. Not all alternative theories have remained only at the popular level. When Mbeki succeeded Mandela as President in South Africa much credence was given to explaining AIDS by poor socio economic conditions rather than the HIV virus drawing on the works for example of Duesberg who denied links between the virus and the syndrome, which he thought was largely iatrogenic or the result of recreational drug taking, whilst others claimed infection rates did not necessarily translate into infectivity.

Up to 2005 there had been a steady progression in the numbers of those living with AIDS from ~ 10 million in 1990 to + 40 million. Since then a decline of ~ 20% has been signaled, with more than this in some countries most recently Zimbabwe. Optimistic health agencies, especially UNAIDS, saw this as a result of wise and successful policies and programs despite funding cuts and especially by the use of ARVs championed by the pharmaceutical multinationals who made huge profits from their sale. But others, especially critical anthropologists, were suspicious that the reported success story was needed to secure ever more difficult funding sources, and less sure for example about the explanations e.g. ABC, involving more stable sexual relationships, more use of condoms, as well as cheaper generic ARVs. which were the bulwark of the campaigns e.g. in Uganda where there has been a rise in incidence amongst married couples since 2006.Many poor countries and communities could not afford the somewhat toxic, and complicated ARVs long term, despite the token largesse of free distribution in some cases. There were too examples of increases in infection (e.g. Cuba) as well as

epidemics of other sexually transmitted diseases in developed countries which were a portal for potential HIV infection. Finally there were doubts that the statistics were good enough to make judgments and indeed the range of estimates officially admitted was more than the decrease in many cases.

3. Geography and Social Structure

Much research in the anthropology of AIDS has been concerned with explaining the evolution of the pandemic in its geographical variation and socio-structural associations. Of central concern is the spatial distribution of the virus. According to UNAIDS about 2/3 of those living with AIDS are in Subsaharan Africa with concentrations in Southern Africa. In 2005 (2010 in brackets when available) the leading countries in terms of (adult) prevalence rates (with a similar pattern for AIDS death figures) were in descending order (rounded figures)-- Swaziland 33% (26%), Botswana (24%),Zimbabwe 20% (15%), Lesotho (23%), Namibia 19%(15%), South Africa (18%) and Zambia 17%(15%). In terms of numbers India (~5.7 million) leads the field followed by South Africa (~5 million) and Nigeria (~3 million). Anomalies in terms of regional averages, though of much less prevalence (around 2%) are found elsewhere (e.g. Haiti, Guyana, Belize, Suriname, Thailand, Ukraine with conversely low rates in eg Gambia, Cuba, Mauritania). Some popular explanations (in the media) for high rates are coarse grained emphasizing poverty or environmental conditions (e.g. Chernobyl for the Ukraine) and for the lower rates Islam or socialism (Cuba) because of respectively constraints on relations between the sexes and better health services.

The first criticism from anthropology has been to query both the size and accuracy of figures. Probably they are far too low, perhaps by Himalayan proportions as the environmental anthropologist Michael Thompson put it when talking of deforestation (x 40) in that region. In the health field recent studies in India of malaria deaths reported by Dhingra et al in the Lancet (www.thelancet.com - on line 21/10/10) claimed that WHO figures were underestimated by 13 times. If the malaria analogy is used the numbers living with the disease would exceed half a billion. In many countries people are reluctant to take tests because of denial, stigma, fear and the very real chances they may lose their jobs, and even if tested do not seek treatment.. The serological status of only about 1% of the population in Africa is known. Death certificates too, if available are often vague. The situation is further complicated in the case of AIDS by changing definitions, or intricate scoring systems for often rare symptoms as in the Bagui (so called after a meeting in the Central African Republic) classification. Countries may manipulate official figures down so as to protect their image and especially their tourist industry, which may be the largest source of income though occasionally figures are exaggerated to secure funds. Exaggeration is more common amongst the hordes seeking research grants who anticipate success only when they are dealing with big problems and of course the sensationalist media, leading Chin to conclude that numbers are considerably overestimated, though not the lethality of the pandemic. The nomenclature reflects the different assessments. The term epidemic is used for lesser expectations moving through global epidemic to pandemic and beyond to end of the world imagery. By the same token the recent decline in numbers may be more apparent than real, part of international agencies trying desperately to show progress particularly in meeting the millennium development goals where combating the epidemic is a priority.

A fundamental difficulty is that country figures are collected and presented in national frames, from which international comparisons are extrapolated. There are about 200 officially recognized nations but anthropologists record many more cultures which are the context in which the pandemic evolves and which show a very considerable variation in probable prevalence rates within and across countries. Globalization, migration and above all the telecommunications revolution have created new subcultures with distinct behavioral characteristics of relevance to the pandemic. Many of these are networks, often transient and fluid, rather than discrete communities, in which individuals may have several coexisting identities and belief systems with for example notably different attitudes to risk.

Some cultural characteristics may be critical in understanding the pandemic. For example anthropologists have noticed a markedly lower prevalence rate amongst some cultures which practice male circumcision explained by a hygienic benefit, though the procedure itself outside clean medical facilities may be a risk in itself. But the coincidences are not always exact. For example Uganda and South Africa have similar rates of male circumcision (~ 20%) but markedly different infection rates. The effects of female circumcision customs are not clear. Pemunta shows amongst the Ejagham (Cameroon) how there is much marriage between those who do, and do not, circumcise girls. Most argue that female circumcision is a dangerous practice and a gross abuse of women's rights though some traditionalists locally think that low rates of HIV amongst some of these peoples is explained by keeping women apart e.g. by female circumcision practice, or the *burka* and other forms of *purdah*.

Lower prevalence rates may also be associated with those cultures which have strong traditional health systems such as Chi (Chinese) or Ayurveda especially the phytotherapeutic elements Western medicine is said to use ~ 70,000 plants familiar to traditional medicine. Staugaard has shown in the heart of the pandemic in Botswana (and Green more widely), that traditional health practitioners so often derided by western medicine as witch doctors, play valuable therapeutic roles not least as herbalists, as well encouraging the placebo effect.. Traditional healers, and midwives may anyway be the only contact point where there is no western doctor or nurse, or community health extension worker, and often can adapt their traditional modes to western interventions or coexist with them. Very often traditional medicine may be not so much a competing as a complementary philosophy explaining ultimately why a person becomes sick or will die in terms of a familiar symbols and rituals which does not preclude or exclude the practical proximate rationalism of germ theory. Many AIDS sufferers return to their villages anyway since there are few facilities for terminal care in the places to which they have migrated.

Anthropologists have also studied closely the socio structural as opposed to the broader cultural characteristics of the pandemic. An important early contribution was that of Udvardy (in Sterky and Krantz) who proposed 28 hypotheses of the link between social organization and HIV/ AIDS with case studies from the Haya (Tanzania), Digo (Kenya), Kpelle (Liberia), Kikuyu (Kenya) and from Burundi. Certain attitudes and behaviors in relation to marriage, gender, sexuality, inequality, etc were suggested to favor or impede the spread of infection. Udvardy noted that there was a coincidence in reports of the disease with descent systems notably the matrilineal societies in Bantu

cultures where the so called female principle was important, broadly located in a belt across central Africa in the Congo, Zaire, Angola, Zambia and Mozambique. In these societies there were lower bridewealth payments than in patrilineal societies which were more polygynous and had institutions such as the levirate. There was more chance of divorce in matrilineal situations since less bridewealth had to be returned to the husband's kin. Women had more independence including in the sexual sphere. However these theories did not take enough account of the massive nature of urban migration when traditional marriage systems and controls broke down, nor of prostitution, concubinage, homosexuality etc in towns Nor of course did the matrilineal model explain the great concentrations of infection in Southern Africa. In Lesotho according to the World Economic Forum women have more liberty than most other countries but Turkon (from the ARG) has argued that high incidence may be explained rather by the constant squabbling of NGOs and community groups.

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Biographical Sketch

David Pitt was born in New Zealand, educated there, in the United States (AFS Scholar California) and at the University of Oxford (Balliol) obtaining his doctorate in social anthropology. (1966). He held Professorships in Canada (Victoria) and New Zealand (Auckland and Waikato - Foundation Chair of Sociology) before coming to work for the United Nations in Geneva (1980), initially at WHO including a period in the Global Programme on AIDS. Since 1988 he has been Chair of the Commission on AIDS, International Union of Anthropological and Ethnological Sciences supported by a grant from ICSU/ UNESCO. He was elected to Fellowships of the Royal Anthropological Institute and the Royal Geographical Society (UK) From 1983 he has also been Chargé de recherches at the Institut Internationale pour la Paix à Genève (GIPRI) elected to the Honorariat (2008).