

# 1. AIDS and social scientists

## Critical reflections

**Paul Farmer**

Fifteen years into the AIDS pandemic, after at least a decade of social-science studies of AIDS, what conclusions might be drawn as we face a future in which AIDS will play an important, if changing, role? First, it is clear that any comprehensive understanding of this new pandemic will require novel alliances between the social and biological sciences. This argument may be made even more compellingly when we turn to the task of designing effective interventions to prevent or treat the complications of HIV transmission. AIDS in all its dimensions seems to demand broad, *biosocial* approaches, and yet work to date is fettered by disciplinary boundaries. Jean Benoist and Alice Desclaux put it well:

“The conditions limiting or promoting (HIV) transmission, illness representations, therapeutic itineraries, and health care practices— none of these subjects are captured by disciplinary approaches. They evade even the distinction between biology and social sciences, so tightly are biological realities tied to behaviors and representations, revealing links that have not yet been fully explored” (Benoist and Desclaux 1995: 363. *Translation mine*).

As if AIDS weren't complicated enough, the pandemic is changing even as we speak. In those settings where antiviral therapy is available, for example, treatment has been hampered by the rapid emergence of drug resistance. The development of an AIDS vaccine, similarly, has been thwarted by rapidly mutating viral structures.

Indeed, AIDS writ large is a moving target. Social responses to AIDS have varied, we know, from setting to setting; such responses have also changed over time. Both cultural variance and temporal trends come as little surprise to social scientists who study AIDS. Take, for example, anthropologists who are witnesses to the advent of HIV to rural regions of the so-called Third World. In the mid-eighties, AIDS presented new challenges to medical anthropology. Some of the challenges were the fundamentally ethical dilemmas, those inherent both in the study of a terrible new affliction for which there is only limited therapeutic recourse and in the deeply vexed question of how anthropologists might best contribute to efforts to prevent AIDS.

Other challenges were more theoretical and not substantially different from the challenges faced by other ethnographers who sought to study, comprehend, and describe new phenomena. The need for a processual approach to the study of illness representations was dramatically illustrated, certainly, when one was witness to the advent of a disorder previously unknown to one's host community. Some of the steps in this

process of growing awareness were easily intuited, but others were revealed by ethnographic research. In rural Haiti, for example, there existed no collective representation of the disorder before the arrival of the new malady; then came a period of exposure, if not to the illness, then to rumor of it. With time and experience, low interinformant agreement gave way to a cultural model shared by the majority of a community.<sup>1</sup> What determined whether or not consensus was reached? In studies of illness representations, medical anthropologists had usually asked, “To what degree is the model shared?” But when studying a truly novel disorder, a new set of questions pertained. How did cultural consensus emerge? How did illness representations, and the realities they organize and constitute, come into being? How were new representations related to existing structures? How did the suffering of particular human beings contribute to collective understandings, and how much of individual experience was not captured by cultural meaning?<sup>2</sup>

And now, new changes — again, biosocial in nature— loom large. The protease inhibitors and other novel drugs raise the possibility of transforming AIDS into a chronic condition to be managed over decades. The advent of effective and specific combination therapy could and should have an enormous impact on what it means to have AIDS at the close of the 20th century. But it is easy to discern two emerging syndromes: an AIDS of the North and an AIDS of the South. On the one hand, we have people with longstanding HIV disease, a decade out from their first opportunistic infection but now receiving highly-active antiretroviral therapy as well as prophylaxis to forestall other opportunistic infections. On the other hand are those with AIDS of the South: young people, many of them women, with early HIV disease who die of untreated tuberculosis or ‘slim disease’.<sup>3</sup> Many would argue that this distinction has always been present but now promises to become further entrenched.

From the beginning, in other words, we have had northern and southern variants of this disease, with many cases of southern AIDS described in, say, New York City. For most people living with HIV, it is not viral sub-types that determine, at this writing, outcome. It is, rather, whether you are rich or poor. The effects of unequal access to resources,

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<sup>1</sup> For more on this process, see Farmer, 1992 and 1996.

<sup>2</sup> Anthropological studies of emerging cultural concepts have been informed by the critique of an ‘empiricist theory of language’, which has been offered by interpretive paradigms (eg Good and Good 1982), and also by work in cognitive anthropology, which has begun shifting its attention from the formal properties of illness models to their relation to natural discourse and thus to context and performance characteristics of illness representations (see, for example, Price 1987). A focus on *lived experience* is crucial to this view, even in a study of the emergence of a collective representation (For a forceful statement of such a position, see Kleinman and Kleinman, 1989). Headway will now be made by merging these groups of concerns with an accountability to history and political economy.

<sup>3</sup> A widening outcome gap may be anticipated if highly active antiretroviral therapy is not made available to those who need it most. This ‘embodiment’ of inequality is more fully explored in Farmer, 1998.

whether preventive or therapeutic, have lent a grim homogeneity to the course of AIDS among the poor. In reading a score of papers from across Africa, for the Sali Portudal Conference, and in reflecting on a decade of work on AIDS in Haiti and in U.S. cities, I am 'underwhelmed' by the differences. This does not sound, perhaps, much like an anthropologist. Why talk of latitude (North/South) and class (rich/poor) before speaking of culture? Perhaps because, for many of us, that AIDS is a culturally constructed phenomenon is not open to doubt. AIDS, like sexuality, is inevitably embedded in local social contexts; representations and responses must necessarily vary along cultural lines. The contribution of cultural factors to the lived experience of AIDS is and will remain enormous.

What such factors have to do with the progress of the pandemic — with rates of HIV transmission and with the course of HIV disease among those infected — is more difficult to discern. At the same time, most of the forces driving the pandemic forward are largely biosocial, rather than merely biological. Political-economic crises of one sort or another are readily linked to the most explosive AIDS epidemics, in Africa as in Haiti.<sup>1</sup> In settings where intravenous drug use is an important mode of transmission, HIV also moves along social 'fault lines', disproportionately afflicting the poor and the marginalized. In fact, it would be easy to argue that poverty and social inequalities are the leading co-factors in the transmission of HIV. Some of us suspect that a truly explosive local AIDS epidemic requires as a co-factor steep grades of inequality.<sup>2</sup>

For these reasons, it is important to pause and take stock as we contemplate an uncertain future. Where is the pandemic going, and how might the social sciences contribute to efforts to prevent AIDS or to alleviate AIDS-related suffering? The Sali Portudal gathering surely represented the most significant roll-call to date of social scientists concerned with AIDS in Africa. Scholars from across the continent were there joined by scores of French colleagues; many other countries were represented as well. We must now ask ourselves, What are the major analytic questions facing social scientists and others who seek to understand the multiple dynamics of AIDS? Can the major factors promoting or retarding HIV transmission be identified and differentially weighted? Can the sexual choices made by individual actors be linked to the various shifting conditions that restrict choice, especially among the poor and otherwise marginalized? Can we come to understand the contribution of the culturally specific — local sexual mores, of course, but also kinship structures and evolving representations of disease — without losing sight of the large-scale forces shaping the AIDS pandemic? Can we investigate the precise mechanisms by which such forces as racism,

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<sup>1</sup> The interrelation between large-scale social forces and HIV transmission has been the focus of my own work in Haiti. For similar analyses of AIDS dynamics in sub-saharan Africa, see the work of Christine Obbo, Maxine Ankrah, and Brooke Schoepf-Grundfest.

<sup>2</sup> The contribution of social inequalities to the spread of HIV and other 'emerging infectious diseases' is explored in Farmer, 1996a.

gender inequality, poverty, war, migration, colonial heritage, and even structural adjustment programs become embodied as increased risk?

To each of these questions I would reply, Why not? Anthropology, the most radically contextualizing of the social sciences, is well suited to meeting these analytic challenges, but we will not succeed by merely ‘filling in the cultural blanks’ left over by epidemiologists, physicians, scientists, and policy makers.

It is also necessary to identify a number of interpretive trends that hobble our understanding of the multiple dynamics of the AIDS pandemic.

— First, there is widespread adherence, among social scientists who study AIDS, to behaviorist, cognitivist, or culturalist *reductionisms*. All of these reductionisms have their own internal logic; each is profoundly desocializing. Biomedical reductionism has led many physicians to regard such social considerations as merely epiphenomenal, but other parochialisms lead psychologists to reify individual psychology, anthropologists to reify culture, economists to reify economics, et cetera. A look back at the burgeoning literature on AIDS reveals other recurrent themes, including a failure to embed data, often phenomenologically sound, into the social context that gives it meaning. A systemic analysis, one both geographically broad and historically deep, is requisite to any sophisticated and dynamic understanding of the AIDS pandemic or its component subepidemics. Current frames of analysis focus overmuch or exclusively on local factors and local actors, running, as noted, the risk of exaggerating the agency of the poor or otherwise marginalized.

It is important to avoid confusing our own desire for personal efficacy with sound analytic purchase on an ever-growing pandemic: HIV cares little for our theoretical stances or our training. Disciplinary blind spots lead in turn to interpretive mayhem. Take, for example, anthropological studies of AIDS. When a population hard-hit by HIV is both poor and culturally remote, the division of labor often leads us anthropologists to explain mortality and morbidity rates as the outcome of unusual sexual or religious customs, leaving poverty and inequality out of the discussion altogether. This error, born, surely, of our disciplinary focus, may be termed ‘the conflation of structural violence and cultural difference’, and its influence may be felt far beyond the confines of anthropology.<sup>1</sup>

— Second, it’s a bad habit to reduce HIV infection to an individual choice and its consequences, and yet the *exaggeration of individual agency* mars much writing on AIDS. Is it possible to explain the strikingly patterned distribution of HIV by referring exclusively to attitude, cognition, or affect? Fine-grained psychological portraits and rich ethnography are never more than part of the story. I, for one, would not hazard to comment on the psychological makeup of Africans with AIDS, and suspect that any quest for psychological ‘predispositions’ is fundamentally misguided. On the makeup of their changing social

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<sup>1</sup> The ‘conflation of structural violence and cultural difference’ in anthropological writings on AIDS is examined in Farmer, 1997; its general contribution to confusion regarding the genesis of suffering is explored in Farmer, 1996b.

conditions, however, much can be said. On the nature of inequality and on the structure of poverty — increasingly, a global process— much can be said. On the mechanisms by which these forces come to alter sexuality and sexual practices, and on Africans' lack of access to both AIDS prevention and treatment, much can be said too. It is thus unfortunate that these topics have been neglected in the biomedical, epidemiological, and social-science literature on AIDS to the benefit of a narrowly behavioral and individualistic conception of risk.<sup>1</sup>

— Third, the *myths and mystifications* that surround AIDS —and slow AIDS research and compromised AIDS services— often serve powerful interests. If, in parts of Africa, structural adjustment programs and wars are somehow related to HIV transmission, who benefits when attention is focused largely or solely on 'unruly sexuality' or 'promiscuity'? If similar forces are related to AIDS in Haiti, why all the talk about *voodoo*? In the United States, in a more honest analytic framework, racism, gender inequality, and lack of opportunity will come as clearly into view as the psychological attributes of those addicted to drugs. In more candid discussion, tax holidays, guaranteed low wages and offshore assembly plants will be the subject of as much discussion as Aid to Families with Dependent Children. In Africa and Haiti, open and honest discussion will push us to explore the effects of structural adjustment programs on HIV risk even if we are more interested in the more traditional topics of medicine and anthropology.<sup>2</sup>

There are corollary points, as well. Some of the variation in accounts of the AIDS pandemic and of its various local subepidemics is useful and complementary. But some of it is misleading, if not outright false. There is not an unlimited number of means by which HIV is transmitted, nor is there an unlimited number of local epidemics, even though each person with HIV comes with personal and cultural 'baggage'.

In conclusion, it is important to recall that HIV cares little for our theoretical stances or our disciplinary training. Everywhere it goes, the virus makes its way from host to host with a surprisingly modest repertoire. Everywhere it goes, it attacks CD4 cells, leading, again, to a fairly restricted number of opportunistic infections. The true —and vast— variation of HIV lies not in its modes of spread or in the mechanisms by which the virus saps the host. It lies, rather, in its clinical course, which varies according to the patient's social conditions, and in the ways in which we respond, socially, to a deadly pathogen. This infinite richness will generate plenty of work of interested social scientists, from psychologists and anthropologists to economists and historians.

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<sup>1</sup> The effects of these 'blind spots' on scholarship have been explored more thoroughly in Farmer *et al.*, 1996, Part II. See also McMichael, 1995, and Krieger *et al.*, 1993, who explore the effects of these disciplinary limitations on epidemiology. In France, Didier Fassin (e.g., 1996a; 1996b) has offered important work on these topics, which are more native to the sociology of knowledge, perhaps, than to anthropology.

<sup>2</sup> See Lurie, Hintzen, and Lowe, 1995; Millen and Lederer, 1998.

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Paul FARMER, *AIDS and social scientists. Critical reflections*

*Summary* — A comprehensive understanding of AIDS in its multiple dynamics requires a broad biosocial view. Social-science methodologies have much to contribute to such a view. A careful review of previous contributions and a decade of AIDS research in Haiti hints, however, at the existence of a number of interpretive pitfalls common when HIV transmission is clearly promoted by “structural violence” —poverty and other social inequalities. Many social scientists, like their clinical and epidemiological colleagues, have been slow to examine this noxious synergy, in part because of a conflation of structural violence and cultural difference, a tendency to exaggerate the agency of the poor, and a willful disciplinarity. These traps lessen our chances for a sound analytic grasp on the AIDS pandemic —a prerequisite, surely, to effective interventions to ameliorate AIDS-related suffering.

*Keywords:* AIDS • social inequalities • sociology of knowledge.

Paul FARMER, *Sida et sciences sociales. Réflexions critiques*

*Resumé* — Une compréhension globale du sida dans ses multiples dynamiques requiert une perception biosociale large. Les méthodologies des sciences sociales ont beaucoup à contribuer pour une telle perception. Un examen soigneux des contributions précédentes et d’une décennie de recherches en Haïti laissent supposer, cependant, l’existence de certains pièges interprétatifs communs, alors que le VIH est clairement propagé par “la violence structurelle” — la pauvreté et d’autres inégalités sociales. Les chercheurs en sciences sociales, comme en sciences médicales et épidémiologiques, ont été lents à examiner cette synergie délétère, en partie à cause de la combinaison d’une violence structurelle et d’une différence culturelle, d’une tendance à exagérer la situation du pauvre, et d’une disciplinarité délibérée. Ces pièges diminuent nos chances d’avoir une prise analytique approfondie sur la pandémie du sida, qui est assurément une condition préalable pour des interventions efficaces afin d’améliorer la vie de ceux qui souffrent du sida.

*Mots-clés :* sida • inégalités sociales • sociologie de la connaissance.