Introducing ARVs in Resource-poor Settings:

Expected and Unexpected Challenges and Consequences

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Abstract. Twenty years after the discovery of HIV, AIDS has become the world’s leading infectious cause of adult death. In most industrialized countries, AIDS mortality has plunged sharply with the advent of antiretroviral therapy. The vast majority of those infected, however, do not have access to modern HIV care, and some experts have argued that introducing such therapy is not a ranking priority. This paper presents the experience of an integrated HIV prevention and care project in rural Haiti in order to explore the challenges to national AIDS programs and other bodies in the “least developed” countries as more resources are made available for HIV prevention and care. The Haiti experience suggests that improving clinical services can improve the quality of prevention efforts, boost staff morale, and reduce AIDS-related stigma. Other lessons learned during the first few years of one of the few donor-supported treatment projects in a very poor country suggest that the full participation of community health workers will be required if HIV prevention and care are to reach the poorest and most vulnerable communities; adjuvant social services must also be part of a good project, as must attention to tuberculosis and other primary health care needs. It is concluded that only a “biosocial framework” drawing on both qualitative and quantitative
methods can hope to assess the epidemiological, social, and economic impact of both the epidemic and responses to it.

On the night of December 2, 1984, an accident released a dense cloud of deadly methyl isocyanate gas from a Union Carbide storage tank in the city of Bhopal, India. The Bhopal catastrophe has had untold and tragic consequences—untold because these included not only thousands of immediate deaths and long-term disabilities, but also because contested versions of what happened and who was responsible were linked tightly to local and transnational inequalities of power. The analysis of anthropologist Veena Das is relevant to any thoughtful consideration of the burden of proof placed on the destitute sick and other victims:

Patients who could not produce documentary evidence in the form of records of hospital admission or proof of having been treated in the first few days of the gas disaster were declared to be “uninjured” regardless of the state of their health at the time of the examination. This disregard of all human and medical ethics is appalling, for anyone familiar with mass disaster would know that the immediate task at the time of disaster is to reach help and not to keep meticulous individual records. All this has been justified on the grounds of bureaucratic and legal necessity.¹

Most studies of the Bhopal disaster show that both Union Carbide and the Indian government failed to inform the public of the risk inherent in storing the deadly gas; even cursory analyses reveal great dishonesty in the statements of the powerful, including certain claims that industrial isocyanates were no more toxic than tear gas. Corporate and governmental irresponsibility is easy to document, as were erroneous commentaries from
medical and public health experts, some of them in the hire of the company. “Yet the people to be declared incompetent and irresponsible,” concludes Das, “were neither the multinational nor the government, but ironically the sufferers themselves.”

Reminders of an industrial accident may seem out of place in a discussion of assessing the impact of AIDS programs among the poor, but the sequelae of Bhopal serve as an important cautionary tale for the tens of thousands of researchers and practitioners who are or will become engaged in documenting the impact of integrated AIDS prevention and care projects in settings marked by both extreme poverty and high rates of HIV. AIDS has been a slow-motion Bhopal in more ways than one. From acute deaths to delayed disability, HIV has already claimed far more lives in India than the world’s most notorious industrial accident. In considering both accident and epidemic, inequalities of power determine both who is at risk—poverty, discrimination, and gender inequality are the engines of the 21st-century HIV epidemic—and who has access to what services. In both instances, the poor and disempowered have been blamed for their own misfortune. Finally, the burden of proof regarding the need for effective care has in both instances fallen squarely on the shoulders of the destitute sick and their allies. Can we show that comprehensive HIV services are “sustainable” in the hardest-hit communities? Can we demonstrate that they are “cost-effective” and a “ranking priority” in the face of other competing demands?

The degree to which the burden of proof might be more equitably shared is the subject of this paper, which presents experience from an integrated HIV prevention and care project in rural Haiti. The paper seeks to redefine the analytic tasks prior to the disbursement of long-overdue funds destined to alleviate the massive suffering caused by HIV and the other plagues of our
times. This year alone, an estimated 6 million people will be killed by HIV, tuberculosis, and malaria.\textsuperscript{4} In terms of sheer burden of disease, these three treatable infectious pathogens—ironically, the leading killers of adults in this, the “post-antibiotic era”—constitute three of the most important public health matters of our times.

How can we shift the burden of proof away from those who suffer from these diseases, or live with high risk of contracting them, towards those with ready access to and control over resources of every description (financial, intellectual, documentary)? Simply asking this question leads us back to basic questions about what constitutes proof and who should be required to provide it.

1. Introduction: Resocializing the AIDS-Resources Debates

AIDS-related debates are as old as the epidemic itself. The XIth Global Conference on AIDS was held in Vancouver in 1996. The theme of that conference was “One World, One Hope,” but delegates from some African nations found the title somewhere between willfully naïve and dismissive of obvious inequalities of both HIV risks and access to care. The dissidents had a banner that read, “One World, No Hope.” They predicted then that the newly described success of combination antiretroviral therapy would not be made available for the poor in Africa and other settings with high burdens of both HIV and poverty.

Those skeptical of our commitment to global health equity have been proven correct. Every year since 1996 should have brought us dozens of reports about how best to deliver antiretrovirals in so-called resource-poor settings. During each of the six world AIDS
conferences held since, we should have been able to count on dozens of reports from donor-supported HIV prevention and care efforts serving the poorest communities affected by HIV.

Instead, there ensued years of debate in which HIV treatment and prevention are presented as discrete, indeed opposed, interventions. We’ve had studies of the variable impact of prevention efforts quite divorced from HIV care, in large part because donor-supported HIV care simply doesn’t exist in the poorest countries. We have a fair number of papers asking and answering with confidence the question, “is it cost-effective to treat AIDS in poor countries?” These cost-effectiveness exercises, which usually conclude that it is not cost-effective to treat HIV disease in settings of great poverty, are based on scant data from the most affected continent, for three reasons. First, the costs of treatment and other “inputs” are rapidly moving targets. Second, the impact of effective therapy on transmission—or on prevention efforts—is poorly understood within settings of poverty. Third, relevant operational research has not been done because the projects do not exist. To do operational research, there must first be operations. “Africa cannot afford to wait two decades to tackle AIDS,” notes Ariel Pablos-Mendes. “Yet, the required research has been scant, owing to reservations about the feasibility of HAART, clinical overconfidence and ethical paralysis.”

This “ethical paralysis” did not preclude, however, transnational research projects that include first-world diagnostics (viral loads, say) and third-world therapeutics. Acrimonious debate regarding the ethics of such research has of course also ensued. As for treatment efforts, we do have a few first-hand reports from across Africa but these are not really donor-supported treatment projects. On the contrary, they are patient-supported treatment efforts. In capital cities from Kampala to Cape Town, antiretrovirals are readily available on the market, just as they
are in every Latin American city surveyed by the Pan American Health Organization.7 These reports are often chilling, since when honest they include stories of patients having to prove that they are able to pay for ARVs prior to enrolling in therapy. These reports, if they are candid, include stories about HIV-affected families in which one sick person is selected for treatment while others in the same family are passed over.

Perhaps we should have been sufficiently prophetic to have foreseen the “unexpected challenges and consequences” of HIV programs that include the full spectrum of prevention and care, but surveys of the literature show us that we have few if any mature, donor-supported treatment programs in the poorest and most HIV-affected countries. What’s our excuse, after almost a decade of experience with antiretrovirals? We can blame the high cost of pharmaceuticals or shrug and point to the manifestly weak health infrastructures in such settings. But if we are honest, we will conclude that our own ambivalence regarding HIV therapy for the poorest has hamstrung comprehensive efforts as much as anything else. It may be assumed that naturally conservative funders, looking for consensus and “safe bets,” would be unlikely to pay for such projects if they are so contested within the very community charged with promoting the health of the globe’s poor.

Whence this ambivalence among the public health community and humanitarian organizations? The impact of highly-active antiretroviral therapy (HAART) in the United States, Europe, Australia, and Brazil has been profound, reducing mortality and even expenditures, often dramatically.8 In most of these settings, there is also evidence of decreased HIV transmission, although one study, conducted in the United States among men who have
sex with men, suggest that increased access to HAART is associated with an increase in “risk behaviors.”

Given strong proof of efficacy and little consistent evidence of adverse impact on prevention in settings of poverty, why are we so reluctant to promote access for the poorest AIDS patients? First, there is a deep rift in the international public health community regarding the treatment of those already sick with AIDS. Richard Feachem, recently named director of the Global Fund for AIDS, Tuberculosis, and Malaria (GFATM), describes the rift in the following terms:

On one side is the opinion: “HAART is too difficult, too expensive, and too prone to divert resources from other priority health investments, fuel drug resistance, and undermine progress in behavioural change. We should not launch into this on a large scale.” On the other side is the position: “HAART is a human right. Therapy that is available to gay men in San Francisco and Sydney should also be available to all infected people everywhere. We have no choice and no alternative. We must act on a huge scale and we must do so immediately.”

Our leading medical journals are devoid of reports of treatment projects in Africa but do contain arguments pitting prevention against treatment. “Data on the cost-effectiveness of HIV prevention in sub-Saharan Africa and on highly active antiretroviral therapy indicate that prevention is at least 28 times more cost effective than HAART” reads the abstract of one recent review. Another self-proclaimed “systematic review of the evidence” concludes that the “most cost-effective interventions are for prevention of HIV/AIDS and treatment of tuberculosis, whereas HAART for adults, and home based care organised from health facilities, are the least cost effective.” Yet these conclusions were based not on real experience but rather on another cost-effectiveness projection from South Africa and on a
report of projected drug costs as applied to a project in urban Côte d'Ivoire.\textsuperscript{13} Finally, what are we to make of papers arguing that one intervention (prevention among commercial sex workers) is far more effective than another (prevention of mother-to-child transmission or treatment) when such analyses are written as if Thailand and Tanzania, say, are experiencing comparable epidemics?\textsuperscript{14}

Second, no one seems to have actually done such projects in the world’s poorest communities, although HIV is now the leading cause of young-adult death in almost all of them. There’s thus a lack of know-how regarding who should receive HAART, what enrollment criteria would be, how to manage drug supply, and how best to monitor therapy in resource-poor settings. There is much speculation but little experience in linking prevention to care in the poorest communities. Yet AIDS care, as Pablos-Mendes notes, “is learnt by doing it.”\textsuperscript{15}

That was precisely our conclusion working in Haiti, the Western hemisphere’s poorest and most HIV-affected nation. We have described this poverty, and its relation to HIV risks, elsewhere.\textsuperscript{16} More than 15 years ago, Partners In Health and its Haitian sister organization Zanmi Lasante began a modest AIDS-prevention effort that was followed, much more recently, by a donor-supported treatment program. Prevention and care efforts are community-based and integrated and have been described in some detail in other reports.\textsuperscript{17} For the purposes of this presentation, I will add that our initial efforts—from the late 1980s until 1995—were focused largely on HIV prevention. Our group was the first to introduce voluntary counseling and testing (VCT) into central Haiti, and the first to develop culturally appropriate prevention tools.\textsuperscript{18} Condoms were promoted and free of charge; sexual education
took place in schools, churches, and community meetings. The impact of these interventions, which reflected the consensus that prevention through education was the best we could offer, was limited by the growing poverty and political unrest that Haiti experienced during those years. And even though our own efforts in rural Haiti were met with some measure of success—seroprevalence in our prenatal clinic has remained stable over the past several years—a growing number of young people returned from cities sick with HIV acquired far from their home villages. By the early 1990s, over 25% of all admissions to our small hospital were HIV-related. By 1995, some 40% of adult admissions were among patients with HIV infection.

By the mid-1990s, we had learned a number of keys lessons, and we drew on these to design subsequent interventions. First, the impact of local HIV-prevention efforts would have no impact in far-away Port-au-Prince or other coastal cities, where the majority of transmission was occurring. Second, the sick would continue to return to their home villages, often to die. Third, fully half of these young people would be sick with HIV-associated active tuberculosis, a proportion rivaled only in certain slums in Haiti’s largest city. Fourth, this substantial subset of patients would not die in the short-term if they were to receive effective TB treatment. Thus in addition to continuing our prevention efforts, we redoubled our efforts to detect and treat every case of active TB in patients diagnosed with HIV infection. From the outset, then, our HIV and TB activities were linked.

In 1995-96, we introduced AZT to our prenatal-clinic formulary and again we learned important lessons. First, the number of women seeking testing during pregnancy rose sharply. Two years earlier, the proportion of women accepting free VCT during pregnancy was
between 15 and 20%. After AZT became available, we learned a fifth lesson: greater than 90% of all women agreed to testing. Most women were of course found to be seronegative, affording important opportunities for prevention. Among women found to be infected with HIV, mother-to-child transmission became rare. More recently, nevirapine further improved the impact of this effort, since it could be given even in tardily diagnosed HIV infection among parturient women.

In 1998, we launched the “HIV Equity Initiative” in order to complement prevention efforts with ARV treatment for those for whom prevention had failed and who were soon to die, in our opinion, without these drugs. The care component includes an uninterrupted supply of antiretroviral agents, but only modest lab infrastructure; CD4 counts and viral loads were not available within Haiti. Use of ARVs was supervised by community-based health workers who are called *accompagnateurs* and who visit patients each day. By the spring of 2002, between 10-12% of the over 2000 HIV-positive patients followed in our clinic receive such therapy (Figure 1). In contrast to the scenario described above, in which African patients were granted access to ARVs by showing they could pay for them, the rural Haitian patients are selected exclusively on the basis of clinical status. A clinical algorithm, described elsewhere, is used to help identify those patients in greatest need.21
The scope of this project has to this day been limited by an inability to find significant donor support for an integrated HIV-prevention-and-care project in rural Haiti. Though we felt we had no choice but to move forward— years ago, HIV surpassed tuberculosis and malaria as the leading infectious cause of young adult death in Haiti— we had to rely on private donations, support from patients (and students) in the United States, and the largesse of a couple of major donors who had supported our work in the past. In short, we would have much more to report in 2002 if we had been able to find even one institutional partner in the donor community instead of encountering, as we have, the argument that such projects were neither cost-effective nor feasible in a setting of such profound poverty. Some have even argued, to our surprise and dismay, that it is “irresponsible” to provide ARVs to the poor.
2. Positive Impacts of Linking Prevention to Care

As argued above, AIDS debates are socially constructed and have often yielded more heat than light.\textsuperscript{22} Those seeking to assess a particular intervention will see, often enough, just what they want to see. It is easy to predict that those who argue against making ARVs available to the poorest will soon point to problems: acquired resistance to these drugs, thievery and sale on the black market, adverse drug effects, diversion of resources from higher-priority projects, the obstacle of stigma, et cetera. But one positive effect of integrating treatment should not be ignored: for over a decade, those living with both poverty and HIV (they are tens of millions strong, even if they have no acronym) have been demanding access to effective therapy. Thus merely introducing donor-supported HIV treatment efforts is positive because it shows we are listening, at long last, to these voices. Such novel efforts strike a blow for equity, no matter what the naysayers may say— and no matter how uncomfortable the public health and scientific communities may feel about the language of social justice or about social justice itself.

But given good-will efforts to assess honestly the impact of a diverse set of interventions in diverse social fields and in the context of epidemiologically diverse HIV epidemics, what models can guide evaluation? How would one begin to assess, in a setting such as rural Haiti, the impact of such programs? We would like to share, here, more of the lessons learned in recent years.

The gold standards for assessing efficacy of AIDS prevention and care are quite different, and both are largely beyond the reach of health care facilities in regions most affected by HIV and poverty. In Haiti or equally poor countries in Africa, even university-affiliated projects would
have as much or more difficulty measuring HIV incidence as they would measuring viral load. Furthermore, these gold standards of measurement tell us little about the impact of treatment on quality of life, on AIDS-related stigma, on staff morale, or on potential impact on families torn apart by having to care for their dying breadwinners.

And yet there are ways of doing a much more comprehensive job of assessing program impact in even the poorest places. The social sciences offer a significant number of methodologies that could help to measure, for example, the degree of community engagement or the impact of treatment on stigma. The social sciences are also better placed to identify and differentially weight the factors promoting HIV transmission in a specific region, since most of these factors are social. The social sciences, including the sociology of knowledge, are able to reveal the means by which scientific knowledge, to say nothing of AIDS debates, is fundamentally socially constructed.

Our own work has drawn heavily on precisely such methodologies, and also on daily reports of activities in the clinic and monthly reports from community health workers. Monthly patient meetings and home visits are the settings for exchanges that shed light on what works and what does not. Such discussions permit project staff to prioritize interventions based not only on economic dicta but also on the wishes of those living with HIV. Charts and laboratory registers provide another important source of information: there is nothing more revealing than regular weights on cachectic patients who are afforded HAART. Demand for HIV testing, and the proportion of positive tests, are also telling.
As one example, the impact on demand for voluntary counseling and testing (VCT) of introducing ARVs has been profound and positive, in our experience. One group, writing about sub-Saharan Africa from San Francisco, expressed their doubts about “quantitative data supporting this argument.” But these doubts are underpinned by neither countervailing “quantitative data” nor by experience in settings in Africa in which demand for VCT was monitored before and after ARVs were made available to the poor. Again, that is because ARVs have not been made available to the African poor. It is possible, however, to chart the rise in demand in rural Haiti by following testing and counseling as documented in laboratory registers and daily reports. Since 1998, demand for such services here in rural Haiti has more than quintupled.

Similar confusion surrounds debate around stigma, which is widely discussed as a barrier to introducing ARVs to Africa. Yet such comments are insufficiently grounded in broader social analyses. The literature is rife with surveys that give us completely discrepant views on how stigma is related to events and processes as varied as sexual comportment, care-seeking behavior, and adherence to antibiotic regimens. So too is there disagreement as to whether access to therapy is associated with a rise or a reduction in risk-taking behavior. This is because questions of stigma and access are inevitably tied to both local social knowledge and to power, both of which are rarely studied in conventional surveys or clinical work. What is true in one setting is false in another, as argued over a decade ago when comparing AIDS-related stigma in rural Haiti to that experienced by Haitians living in North America.

There is no data to support the hypothesis that AIDS-related stigma prevents introduction of effective therapy. On the contrary, the transformation of AIDS from an inevitably fatal
disease to a chronic and manageable one has decreased stigma dramatically, in Haiti. To cite the experience of one patient, who asked that his words and photographs be used in this paper, “I was a walking skeleton before I began therapy. I was afraid to go out of my house and no one would buy things from my shop. But now I am fine again . . . My wife has returned to me and now my children are not ashamed to be seen with me. I can work again” (Figure 2).

**Figure 2: “Now my children are not ashamed to be seen with me.”**

Our own experience in Haiti suggests that, even without making claims for reduced transmission— claims that would be easy to buttress using indirect evidence— it is clear that the impact of a “low-tech” HIV prevention-and-care project could be measured without importing a new and costly “evaluation infrastructure.” Table 1 lists some indirect indices of positive impact and the potential sources of data that might be made available in even the poorest communities.
### Table 1. Assessing Impact: Possible Data Points

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<tr>
<th>Impact on patient outcomes</th>
<th>Patient charts; weight; ADLs</th>
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<tr>
<td>Impact on burden of disease</td>
<td>Prenatal screening</td>
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<td>Response to local calls for equity</td>
<td>Community forums; focus groups</td>
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<tr>
<td>Reduced mortality</td>
<td>Chart review; CHW reports</td>
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<tr>
<td>Reduced rates of hospitalization</td>
<td>Daily reports; chart review</td>
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<tr>
<td>Reduced stigma</td>
<td>Ethnographic inquiry; case histories</td>
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<tr>
<td>Improved staff morale</td>
<td>Staff meetings; ethnographic study</td>
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<tr>
<td>Increased demand for VCT</td>
<td>Laboratory registers; daily reports</td>
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<td>Meeting public health goals</td>
<td>External MOH evaluation</td>
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3. **Expecting the “Unexpected” Challenges**

Because our own project was integrated into an existing tuberculosis-control program, we were able to anticipate some of the likely challenges to the project described above. We have learned many lessons from tuberculosis control. We were nonetheless surprised to read one response to our project that termed as “alarming” our alleged “dismissal of the ‘spectre of acquired drug resistance.’”\textsuperscript{26} Drug resistance was not an unanticipated challenge, nor did we dismiss it: in fact, our reliance on TB outreach workers reflected our conviction that supervision of therapy is one of the best ways to slow the incidence of inevitable mutations (a point underlined in the very paper to which our World Health Organization colleagues were responding). But more important than supervision is the social support that community health workers can offer to patients and their families; it is for this reason that they are called, in the Haiti project, *accompagnateurs.*
Eventually, however, patients receiving combination therapy are likely to “break through” even the most scrupulously followed regimens. Existing ARVs are suppressive, not curative. What would an ideal second-line regimen be? Would partner institutions in capital cities or in affluent nations perform resistance testing, or would an empiric second-line regimen be best for treatment failures in settings such as Haiti? There are a host of similar questions, and we would have at least preliminary responses to them if only we’d had the foresight to integrate, years ago, HIV prevention and care in resource-poor countries. It is time to catch up, and to anticipate these challenges, some of which are listed in Table 2.

Table 2. Anticipating Unanticipated Challenges: The Haiti Experience

- Managing concurrent health problems, including OIs common in poor communities
- Assessing generic drug quality
- Assuring uninterrupted drug supply (forecasting demand) and storage
- Maintenance/servicing of laboratory equipment
- Drug-resistant HIV; second-line regimens
- Use of fixed-dose combinations of ARVs
- Training for and monitoring rational use of ARVs
- Managing/referring HIV among patients from distant regions
- Management of scarce resources in settings of extreme poverty
- Effective integration of traditional healers, including birth attendants
- Responding to unemployment, lack of food, housing, and clean water

Table 2 suggests that the most daunting challenges for which scale-up projects must be prepared are those having to do with the poverty of our patients. One of the most difficult parts of our work in Haiti has been what to do when a previously bedbound patient finds herself symptom-free on therapy and facing a houseful of hungry children. Many of our
patients—more than half of the women in our cohort—worked previously as servants in the city; many of the men had worked as manual laborers, often cutting sugarcane in the Dominican Republic. In both instances, local and international authorities have spoken of conditions akin to slavery. Sending patients who again feel able-bodied back to such situations is objectionable on many grounds, but surely the answer is not to conclude that they should never have had access to therapy in the first place. We have decided, on the contrary, that our primary loyalties should be to precisely these individuals. Yet we have already hosted, here in Haiti, visitors who have wondered out loud whether it’s a good idea to resuscitate the dying if they are to face the same problems that led to their infection in the first place. But where does the social lesion lie? It would be high irony if treatment projects were to be damned because the medications are often so effective in bringing back poor people from the brink of death.

Many such phenomena are to be understood not as complications of our interventions but rather as symptoms of growing social inequalities. Who is to be blamed if a hungry crowd sacks a warehouse full of powdered milk destined for the infants of mothers who received ARVs during pregnancy? Again, where does the social lesion lie? It is of course expedient to consider this a reflection of “local corruption” rather than of the apparently insatiable appetites of the affluent world, but there is far more evidence supporting the latter hypothesis. If in the poorest countries “minimal absorptive capacity” thwarts the ability of local public authorities to use donor funds wisely, is this due primary to the “brain drain,” itself linked to growing transnational inequalities, or to the incompetence of local public authorities? Where, precisely, does the lesion lie?
Each of these challenges will be encountered across the African continent and indeed in all communities struggling with both HIV and poverty. Honest reflection on these problems will lead us back to transnational questions regarding the distribution of resources, as we have argued elsewhere.27

4. Asking the Right Questions: A Biosocial Model to Assess Impact

The last two decades have taught us a great deal about failure, and how it is best measured: new HIV infections and AIDS deaths are the grim gold standards. A lack of decent medical care and effective prevention strategies (including a vaccine or women-controlled barrier methods) are others. But a broad range of other events and processes stand as markers for failure: AIDS-related discrimination, unsafe blood transfusions, unattended childbirths, unclean water, and a lack of social services for HIV-affected individuals and families would figure high on this list of indirect markers.

And that’s the analytic rub: we don’t know how best to analyze such a diverse set of inextricably related problems. What evaluative framework might guide us as we attempt to measure phenomena as varied as HIV incidence and AIDS-related discrimination? How might we assess the impact of new projects? How do we address poverty and gender inequality in AIDS prevention and care, if they are so manifestly related to HIV transmission and outcomes? The best framework for analysis and evaluation would need to be robustly biosocial, since the phenomena it attempts to describe are nothing if not both biological and social. The framework would draw on conventional epidemiology, certainly, but also on complementary “resocializing” disciplines in which patients’ voices and experiences are heard and documented.
Anthropology and sociology are among these disciplines, as is the sociology of science. Alas, ethnographic inquiry and community health worker reports are not often regarded, within public health, as robust sources of information. But the fetishization of numbers means that mathematical modelling, which is often based on more slender evidence, is regarded as not only pertinent but necessary. Cost-effectiveness analysis holds sway among policy makers even when it is not underpinned by experience or empiric research.

The analytic challenges are before us right now, since several previously underfunded projects are soon to receive resources. Many efforts will be called to serve as pilot projects seeking to “scale-up” services to larger populations. To quote Richard Feachem again: “These sites would achieve three things. First, they would bring HAART to tens of thousands of infected people in an effective way. Second, they would be islands of good practice where new drugs and new delivery techniques are continually being applied and evaluated and a major learning experience is going on. Third, they would provide powerful demonstration sites where the cost, impact and feasibility of using HAART in resource-poor settings could be clearly seen.”

To be good demonstration projects, these projects will need a new set of criteria for the evaluation of donor-supported projects seeking to provide HIV prevention and care services to the very poorest communities. Could this new evaluative framework be anything other than biosocial? It must assess not only impact on morbidity and mortality but also questions of stigma and equity; it must offer a resocialized understanding of how inequalities come to take their toll through disparities of risk for infection, radically different courses of disease, and
disparities of access to proven therapies (Table 3). We need, now, a novel synthesis of complementary methodologies, both quantitative and qualitative. We need to value the input of community groups, including community health workers and others who deliver services directly to those in greatest need.

Table 3. Setting Priorities for Evaluating AIDS Prevention and Care Projects

- Number of patients with access to effective care
- Serosurveys in sentinel populations (e.g., prenatal clinics)
- HIV prevention checklists (sex education, condom distribution, et cetera)
- Number of person-hours of prevention through IEC
- Number of sites offering PMTC
- Number of accompagnateurs supervising therapy
- Reinforcement of public health infrastructures
- Creation of coalitions to expand and “harmonize” prevention and care services
- Transparent reporting of expenditures
- Avoidance of drug stockouts

To rely overmuch on existing frameworks will mean that, once again, the poorest communities will be left behind, since they do not have the “evaluation infrastructure” necessary, for example, for an NIH-funded research project. It is no accident, of course, that the communities most affected by HIV are those without an NIH or an Institut Pasteur.

We need new operational research that is sufficiently biosocial. But most of all we need services for those who have gone without them. A certain confusion regarding the quite different goals of research and service has hobbled effective responses to HIV disease in the poorest communities. The point of bringing new funding to allay the suffering caused by
AIDS, tuberculosis, and malaria was not merely to mimic existing transnational research projects, already struggling with serious ethical dilemmas, but rather to remediate inequalities of access to proven therapies. This goal should be embraced without apologies.

Embracing this goal helps us to answer the question, What is the purpose of such operational research? Not merely to please skeptics, one hopes, since accountability should be, for a change, to the afflicted rather than the privileged. The very purpose of this research is to do a better job bringing the fruits of science and public health to the poorest communities. The purpose of the new funds is also to help us to better promote the daunting task of furthering broader agendas of public health. This will of course mean taking on, within nascent HIV projects, not only tuberculosis but also malaria, eclampsia, hookworm, and the long list of maladies transmitted by unsafe drinking water. This will mean making common cause with community health workers and others in the trenches. In the end, the burden of proof should lie on those shoulders of those who argue against making remediating inequalities of access to prevention and care our top priority in international public health.

5. Conclusions: Removing the Burden of Proof from the Sick

With the exception of $100,000 start-up funds from a foundation based in Haiti, the HIV Equity Initiative in Haiti has never received support from a major foundation or international body charged with responding to AIDS. This will all change in the coming year if Haiti is awarded funds from the GFATM. As we and other groups based in regions in which poverty and HIV are the ranking threats to health contemplate the advent of new resources, we need to ask hard questions of ourselves and also of those who will evaluate the use of these funds. In seeking to promote accountability, will we develop yet another set of burdensome
reporting requirements that will force us to hire expensive consultants from far beyond the boundaries of afflicted communities? Or will we seek innovative and realistic means of evaluating the impact of long-overdue investments?

In contemplating these challenges, I am reminded of Veena Das’s devasting assessment of what happened in the aftermath of the Bhopal disaster. The burden of proof, she shows, was on the shoulders of the poorest victims of the disaster. What’s more, the rules—legal and medical—of the game made sure the burden remained there. We must change the rules of the game if we are committed to standing with the poorest communities, which are precisely those beset with both HIV and a lack of medical and evaluative infrastructures.

Within every community beset by poverty and HIV are scores of willing individuals who wish to be trained to serve as community-health workers. Working with these *accompagnateurs*, we can develop lower-cost means of assessing impact so that resources may be channeled into food, water, and improved housing for HIV-affected families. Such resources are better spent on salaries for health workers than on yet another round of per diems and consulting fees for “experts.” Such resources can be spent on improving TB diagnosis and treatment, and on linking HIV services to prenatal care (including the prevention and management of eclampsia and other third-trimester catastrophes). Indeed, we can use this moment to atone for our collective inattention to a host of preventable or remediable afflictions.

If we succeed, we may at the same time develop truly novel strategies for assessing the impact not of our largesse but rather of our long-overdue attempts to remediate the obscene disparities of risk and access that characterize the global AIDS pandemic.
References


2. Ibid., p. 158.


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