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**HIV INFECTION IN CUBA:
FAILURE OF SOCIALIST HEALTH POLICY?**

by Victoria Anne Behrman

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"Medicine is a social science, and politics nothing but medicine on a grand scale." -Rudolf Virchow

"One of the most remarkable features of the pandemic of HIV infection and AIDS is a relentless capacity to focus attention on long-standing, complex and unresolved social issues." -Jonathan Mann

"Todo mirar rezuma falsedad, porque es lo que nos arroja más afuera de nosotros mismos." -Julio Cortázar

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I. INTRODUCTION

In the final years of the eighties HIV, the virus causing AIDS, spread to almost all corners of the globe. Current estimates are that a new person becomes infected with HIV every minute.¹ Clearly the AIDS pandemic is a crisis of global proportions, demanding international cooperation in the search for solutions. And this cooperation has indeed emerged: by mid-1988, 176 countries had joined the World Health Organization's global AIDS reporting network.² Yet the nations of the world have responded to the crisis in a variety of ways, with varying degrees of speed, diligence, funding, and concern for civil liberties. Nonetheless most countries have generally followed the recommendations of the WHO, which has cautioned against quarantine and ostracism of HIV-infected people.

One country, however, has not followed these recommendations. Cuba, a nation which provides free and technologically sophisticated health care to all of its citizens, has made the decision to pursue a drastic policy of mass testing and isolation of seropositives. These policies are unique in the world, and have earned Cuba a great deal of criticism, from observers of widely different political convictions.

This paper will provide a substantial understanding of the nature of the Cuban model by considering that country's

experience in detail. Some aspects of the Cuban experience which will be described include the context and history of the policies, their consequences and the true reasons such a path was chosen. Competing explanations for the present policies, considering such things as political and cultural factors, will be considered.

With this thorough description of the Cuban experience as a background, some major ethical, legal, and social questions will then be raised. In particular, what is the theoretical, ethical and legal basis of a policy of mass screening? For a policy of isolation? How does the Cuban experience fit with or differ from that of the rest of the Caribbean and Latin America? On what basis has the Cuban strategy been criticized? What is the political and theoretical motivation for these criticisms?

In the second half of the paper a more specific set of questions is posed, in an effort to provide a rigorous ethical and policy analysis of the Cuban model. First, is there any basis to the claim that the Cuban model has been effective? And in what way are claims of effectiveness and of moral correctness related?

There are two ultimate goals of this paper. The first is to evaluate the lessons of the Cuban experience purely on its own merits and in its own context. Is the Cuban strategy a model for Cuba? Or an example of the worst elements of the Cuban revolution? The second is to

consider the usefulness of the Cuban experience for the rest of the world. Can Cuba serve as a model for other countries to emulate, or is the Cuban strategy a negative lesson, an illustration of the horrors of prejudice, hysteria and ignorance?

II. BACKGROUND: HEALTH CARE IN CUBA

Prerevolutionary conditions.

It is no secret, and need not be elaborated here, that most Latin American countries carry a heavy burden of infectious disease, preventable deaths and poor health status indicators. Prerevolutionary Cuba was no exception to this rule. There was a long tradition of public health efforts of various kinds; yet disgracefully, and for a variety of reasons, there was extreme inequity in the distribution of health, with urban areas consuming the vast majority of health resources and rural areas suffering extreme neglect.³ There were several forms of available urban services, including a long tradition of prepaid medical plans (something like our HMO's), known as "mutualist" organizations. Some of these were based on old, conservative Spanish ethnic groupings; others were more recent and less exclusive but nonetheless excluded blacks. Private practice existed but tended to be blended with these collectivized forms of health care delivery, or even with the public sector hospitals (e.g., some public hospitals had special beds for private patients).⁴ There was a large community of physicians with long-standing traditions, a contentious and economically insecure history, and a sense of having struggled to achieve a stable position in society.

Many factors motivated the guerilla war against the

Batista dictatorship. Among these factors was the recognition of inequity in health care and the injustice of preventable illness. The medical profession played a role in the overthrow of the dictatorship and helped in the early planning stages of the new revolutionary society. And a thorough restructuring of the health system was an early and high priority for the new government.

Health care in the new Cuba: a brief outline.

The following are the five principles of health care established by the revolutionary Cuban government:

- (1) Health care is the right of the people, thus access is universally equal and free of charge.
- (2) Health care is the responsibility of the state.
- (3) Preventive and curative services are integrated.
- (4) The population participates in the development and functioning of the health care system.
- (5) Health care activities are integrated with economic and social development.⁵

Each stage in the development of modern Cuban health policy has in some way been informed by these principles. However, it would be a mistake to assume that all of the developments in the Cuban health care sector since 1959 may be explained with reference to these explicitly stated principles. Other factors also influenced the development of the new Cuban health care sector, as will be seen. It should also be noted although these principles seem idealistic, they may contain some flaws which are reflected in the Cuban health

care system in the form of difficulties, structural problems or imperfections. More on this shortly.

The Cuban health care system may be considered to have passed through four stages since 1959.⁶ The earliest period encompassed the first decade of the revolution, 1959-1969, and was a period of dramatic change focussed on the most pressing current problems. The most pressing problems were the extreme lack of services in rural areas, high mortality and morbidity from infectious disease, and a shortage of personnel. Accordingly, the main efforts of this early period were to provide services in rural areas, to control the major infectious diseases through national, disease-specific vertical campaigns, and to train large numbers of personnel (especially M.D.'s) as quickly as possible. There was widespread popular participation in the vertical campaigns of this period. The early period had profound effects on rural Cuba, on the university, and on the organization of the ministry of health. However, much of the existing structure of urban services, specifically the many "mutualist" societies, were not immediately dismantled. Nonetheless, this period saw a gradual move towards the establishment of a unified national health system, beginning with the reorganization of the ministry of public health (MINSAP) in 1962.

The second stage in the development of the Cuban health care system (1970-1974) could be called the period of

consolidation. At the beginning of this period, all health services were finally consolidated into a single system (the mutualist organizations were phased out). The policlinic was also developed at this time. This was the first major national strategy for providing community-based primary care in all areas. Other developments of this stage included better data collection and some new vertical programs.

During the third period, 1975-1984, the policlinics were further developed and implemented in all parts of the country. The developments in health care during this period took place in the context of important changes in broader Cuban society. Specifically, local democratic structures collectively known as 'poder popular' were developed. One aspect of 'poder popular' was the creation of locally elected councils which were given some power to affect decisions made about the health care in the area, specifically, they had some input into the running of the policlinics. Thus, although they were tied in with a regional hierarchy controlled from above, the policlinics were intended to be the Cuban version of community-oriented primary health care.

This stage was known as "medicine-in-the-community." It constituted a major effort to provide community-oriented primary care to all Cubans. Some of the features of medicine-in-the-community were as follows: The policlinic was given the total responsibility for the health care of

the population of a given area. Each policlinic employed four types of "general specialists", i.e., internists, dentists, pediatricians, and obstetrician-gynecologists. The policlinic was supposed to provide continuity for patients when they were referred to more centrally located hospitals for specialized care. Preventive and curative services were supposed to be coordinated by the policlinics.

Medicine-in-the-community was successful in several ways. Universal access was largely achieved. The health of the population improved. There was some local input into decisions that were made about local health services, although popular participation was largely on the level of implementation, and not planning, of health policies.⁷ However, there were some major problems in medicine-in-the-community. First, the areas served by the policlinics were large (up to 30,000 people), and those who worked at the clinic were not well integrated into the community that they served. Thus in practice the community and its medical care-givers did not enjoy a close mutual understanding, and except for some large vertical programs, preventive care was infrequent and ineffective. ("It was a rare well person who used individual services in a preventive manner."⁸) Also, it was found that there was little continuity of care, due to the use of several specialists instead of one central care-giver, and that those who were sent to regional or provincial hospitals for specialized care were not followed

by the local team. For all these reasons, a new program was initiated in 1985: the family doctor program. This new program marks the beginning of the fourth and current phase of health system development.

The goal of the family doctor program is to have 20,000 family doctors practicing at the neighborhood level by the year 2000 (A doc on every block). The family doctor has a nurse as assistant and serves approximately 600 to 700 people, or about 120 families. The usual daily work pattern in urban areas is for the doctor to have office hours in the morning (as well as some evenings and weekends), and in the afternoons to make field visits to people's homes, to visit patients in the hospital, and to accompany other patients who needed to see specialists. (In rural areas, the hours are modified, for example to alternating in-office and home-visit days, since people may live quite far apart.⁹) The idea is to make personalized professional care available to all, the well as well as the sick. The small scale of the program makes it possible for care-givers to be familiar with (and in contact with) everyone and thus facilitates effective preventive medical care. The polyclinic serves as a backup. As of January 1989, 37.4% of the population was covered by the family doctor program; the remainder continued to use the old polyclinic model.¹⁰

With that quick romp through 25 years of revolutionary health care as a background, let us step back for a moment

and consider the overall trends of the Cuban model. What are its strengths and weaknesses? It should first be said that there is little disagreement (except from the most conservative critics¹¹) about some of the major successes of the revolutionary Cuban health care system. Thus it is almost universally recognized that in a very short space of time Cuba has dramatically reduced its infant mortality, increased its life expectancy, largely eliminated many other infectious diseases, and so on. The last case of polio in Cuba, for example, was in 1963 - this was several years before polio was defeated in the U.S.¹² These successes are quantifiable and the statistics they are based on are arguably very reliable.¹³

However, there are of course legitimate criticisms of the Cuban health care system. One criticism is that it is an expensive model which relies too heavily on the use of doctors and does not make use of the lay health workers who have been so widely praised since the Alma-Ata declaration in the late 70's. David Werner makes this point very forcefully in his critique of the Cuban model:

A cost effective approach would be to facilitate a skills pyramid in which the bulk of simple, everyday health problems could be tended to by the people themselves with the assistance of modestly trained but readily accessible paramedics and community health workers. Such a system would reserve costly, more highly trained medical professionals for only those major problems that require their special skills. Cuba, however, has chosen to use highly trained

professionals not only to cover every aspect of curative medicine, but also to oversee community and preventive health activities.¹⁴

Werner goes on to argue, convincingly, that people don't always get higher quality care from doctors than from lay health workers, and that a good deal of self-treatment does continue to take place in Cuba (e.g., pharmacists sell a lot of over-the-counter and prescription drugs directly to the public). This supports the view that self-treatment should be legitimized and upgraded.

Werner's arguments may have some validity but they are not the last word on the peculiarities of the Cuban model. What he sees in Cuba is a very rigid system which is almost incapable of responding to popular pressure for change. (He ridicules what he calls "the myth of 'poder popular'.") Yet seven years after his article was written, the family doctor program was begun, and this was undeniably a major innovation which addressed at least several of the important problems of the previous model. Some researchers have argued, in fact, that the success of the switch to the new family doctor program is evidence of a high degree of flexibility within Cuban decision-making structures:

The family physician program was administratively initiated at the highest decision-making levels in the country, receiving the direct attention of the President and the Minister of Public Health. It was a response to unrest and dissatisfaction among the population expressed through their behavior and by direct complaints to

local and national authorities, through ad hoc and officially established channels...Thus the Cuban health care system changes from the bottom up and from the top down.¹⁵

Another and perhaps more serious charge that Werner makes about the Cuban health care system is that is disempowering. He looks at the founding principles of the Cuban health care system and claims that they are self-contradictory:

If health care is the full responsibility of the state, does this not entail restricting or depriving the responsibility of individuals and communities for their own health? And in the long run is such expropriation of responsibility healthy? If the state takes over full responsibility for people's health, yet insists that people must participate in health matters, then in what irresponsible, subservient way, are the people obliged to participate?¹⁶

David Werner wrote these lines three years before the first description of acquired immune deficiency syndrome in the United States, and eight years before Cuba reported its first AIDS death. Yet they have an eerie appropriateness to the case at hand. Is Werner correct in his sweeping condemnation of the Cuban health care system as a disempowering model? A thoughtful approach to analyzing the doctor-based Cuban model might begin, not by condemning it according to preconceived ideas about good and bad health care delivery systems, but rather by asking how it came about.

Roots of the Cuban model.

This section will touch on some of the historical roots of the revolutionary Cuban health care system. It could be argued that in a number of ways, the revolutionary Cuban health care system is linked to its past and to the traditions of Cuban medicine, and that to understand modern Cuban medicine one therefore needs to look at this history and these traditions.

For example, one might begin by recognizing that throughout much of the 20th century Cuba has had a heavily doctor-based medical system and a large and powerful community of doctors who have been active in national health policy debates. Thus it is not surprising that post-revolutionary health care has continued to be doctor-based. Cuba also has a tradition of biomedical research and application of that research to public health programs. Thus for example, Carlos Finlay, Cuba's most famous doctor, discovered in the 1880's that yellow fever is carried by mosquitos. One might legitimately see Cuba's current emphasis on biomedical research and vertical public health programs as the continuation of a proud tradition.¹⁷

There are several other ways in which history may have influenced the course of events since 1959. Ross Danielson argues that the struggles among doctors over mutualism and other forms of health services in the decades before the socialist revolution had profound effects on the forms of

health services after 1959. Specifically, he argues that:

[one] consequence of mutualism is that it lay a basis for a collective orientation to medical work and for the eventual suppression of private practice under socialism. For while mutualism may have been misdeveloped, private practice remained, by the standards of comparable societies, underdeveloped... [the events of this period] preempted private practice and launched elements of the philosophy of social medicine in the organization of clinical practice and the ideology of the medical profession.¹⁸

Another historical event which influenced the course of events in Cuba's new health sector was the flight of several thousand doctors in the early 60's (1/3 had left by 1963). The effect of the flight of the doctors was profound. The need for more doctors appeared urgent, naturally, so a great emphasis was placed on their training and utilization. The departure of so many of the faculty at the medical school, meanwhile, left the remaining doctors with "sense of solidarity amidst an embattled university within an embattled and righteous society."¹⁹ The image of the new doctor, dedicated to the service of society, was in this way engendered.

Summary

In sum, health care in Cuba is a heavily doctor-based system, organized hierarchically, on a regional basis. Comprehensive and complete Western medical care is provided

to all free of charge, and care is increasingly personalized and community-based. Sophisticated tertiary care is available. Cuba makes little use of traditional medicine, of self-help or self-care programs, or of lay health workers. Health policy and planning are done on a national basis and local input into major policy or planning issues is limited. However, there is some opportunity for the general populace to contribute opinions and ideas into the implementation of policy on a local level.²⁰

The organization of the Cuban health care system must be explained with reference to its history, both recent and distant. Every revolution, regardless of its profundity, necessarily carries burdens and benefits of the old society into the new one - these effects may be seen within the Cuban health care system. Likewise, the experiences of the first 25 years of revolutionary health care in Cuba helped to shape the social conditions of medical practice in Cuba in the mid-1980's. It was in this context, within these conditions, that "El flagelo mortal" arrived in Cuba, and the Cuban response to AIDS developed.

III. AN OVERVIEW OF HIV POLICY IN CUBA

At first glance through the newspaper accounts of the past several years, it might seem difficult to give an objective and truthful account of Cuba's policies regarding AIDS; the political perspective of the author informs at least the tone - and very often the substance - of almost every article written on contemporary Cuba. One researcher comments,

to write fairly about Cuba is a special challenge insofar as almost no one does so. Left-wing publications...can see no wrong in Cuba... On the other hand, right-wing interviewers... are so monotonously denigrating that they, too, are hard to take seriously.²¹

These extremes of perception are vividly evident among observers of various political perspectives in discussions of AIDS in Cuba. Adding to the difficulty of reporting on this topic is the extremely guarded attitude of the Cuban authorities regarding their AIDS policies. Access to the isolation facility near Havana, for example, is extremely difficult to obtain. Only a handful of domestic journalists, much less foreign visitors, has been granted permission to visit it. However, some clarity regarding factual details has been obtained, in part via personal interviews by the author with government officials in Cuba. Furthermore, some objective facts have sifted down through the rhetoric of the relatively scarce published reports over the last few years. What follows is a historical sketch of

AIDS policies in Cuba and a description of the present situation. Some questions remain unanswered; these points of disagreement among observers of various political stripes will be described in due course.

The beginnings of the policy

According to officials from the ministry of public health (MINSAP), the Cuban government's response to AIDS began in 1983, when several MINSAP officials attended a PAHO workshop on AIDS in the Americas.²² After reviewing the information in this workshop, MINSAP officials decided to set up a national commission to study the problem. At this time a decision was made to restrict the importation of blood products. The initial restrictions revealed a tendency towards a judgmental, stereotypical "blame the other" attitude towards the disease; capitalist countries were seen as the source of contamination:

One of the first measures taken was the prohibition of hemoderivatives...gamma globulins of different types, as well as any type of hemoderivative originating from plasmas processed in capitalist countries with AIDS. The alternative used... was that of importing only from socialist countries and to proceed developing this production in our country in existing laboratories designed for biologics of this type.²³

Later, the restrictions were expanded to a wholesale decision not to import blood from anywhere.

As early as May of 1983 a national diagnostic screening program was implemented.²⁴ All hospitals were asked to give

weekly reports on patients who presented with Kaposi's sarcoma, repeated bouts of pneumonia, generalized lymphadenopathy, or other infections, signs, or symptoms characteristic of AIDS. In other words, there was definitely sharing of information among health professionals in the early 80's. However, public information about the disease seems to have been quite limited during this time period.

In late 1985 the first commercial tests for anti-HIV antibodies became available on the international market. The availability of the test dramatically changed the picture in the minds of the health planners at the Cuban national commission on AIDS. It was at this time that the aggressive Cuban strategy was planned. First, a series of objectives was laid out, including the following key points:

- (1) to determine who were the high risk groups and what was the seroprevalence within these groups
- (2) to establish a monitoring system which would recognize cases of AIDS
- (3) To study the circulation of the virus by means of donated blood and to eliminate the possibility of transmission through blood donations
- (4) To establish an educational program
- (5) To carry out scientific studies of the illness
- (6) To consider whether the disease could be contained.²⁵

These objectives were to be met via the following strategies:

- (1) To establish 42 diagnostic sites in which antibody testing could be accomplished, and to acquire the testing equipment and necessary laboratory facilities to carry out the tests.
- (2) To train technicians to carry out the tests in these laboratories and in all blood banks.

- (3) To teach all medical personnel, both within and outside the country, about AIDS
- (4) To develop educational materials for risk groups and the general population.
- (5) To acquire the resources necessary to develop domestic test kits in order to avoid the costly importation of these materials.
- (6) To institute a broad program of screening and isolation of seropositives.²⁶

The epidemiological studies which began in late 1985 formed the base of the Cuban plan. These seroprevalence studies were initially focussed on those considered at high risk. The first group systematically studied was those who had been out of the country since 1981; the second group was those who had been out of the country going back to 1976. Then other groups were studied including hemophiliacs, persons attending STD clinics, and sexual contacts of seropositives.²⁷ Preparation was also made to carry out broader screening; (later screening studies included hospital in-patients, pregnant women, and entire towns.) By May of 1986 complete screening of all blood donations was implemented. Buying the initial testing equipment and setting up testing facilities cost over \$3 million, according to Hector Terry, vice-minister of public health. Such a sum is an enormous amount for the Cuba, where foreign exchange is very scarce.²⁸

In April 1986 Cuba reported its first AIDS death to PAHO.²⁹ During that same month the sanatorium "Santiago de las Vegas" was established on an estate known as "Los Cocos," in the outskirts of Havana near the village of El

Rincón. It had 24 residents. There was no official announcement of the opening of the facility.

In the first months of 1987 right-wing Cuban exiles in the U.S. began to criticize the Cuban government's handling of the AIDS epidemic, although full information about the policies had not yet been publicized. The main charges in this initial stage were that Cuban foreign policy in Africa had resulted in large numbers of infected Cubans returning to the island, that the extensive testing program was evidence of widespread AIDS in Cuba, and that the government was covering up the actual numbers of cases that it had on its hands.³⁰ Ironically, some right-wing commentators during this early period caustically derided the Cuban government for having insufficiently stringent prevention policies.³¹

Partially in response to some of these charges, the Cuban government began to explain the policies more openly. The Ministry of Public Health wrote a long, formal and informative declaration which detailed the Cuban AIDS program, and printed it in Granma on April 17, 1987. The following day Fidel Castro gave a press conference in Havana in which he answered questions about (among other things), the report on AIDS.³² The report contained the information explained above and supplied the latest statistics. At that time (April 1987), 677,000 people had been tested and 108 Cubans had been found seropositive. Of these 108 no one was

sick yet and all had been placed in the isolation unit, which was described as a sanatorium, not a hospital. Of foreigners who were in Cuba for extended periods of time, 20,000 had been tested and 107 found seropositive; these 107 were sent home. All Cubans returning from abroad were required to undergo the blood test and to have a follow-up test six months later.

The report also revealed much about the fundamental thinking of health planners in Cuba. They made it clear that they believed it was possible to control transmission by means of isolation. They also stated two other reasons - some would call them justifications - for the creation of the isolation unit: to study each seropositive case clinically, and to attempt to prevent the progression of the disease, from asymptomatic seropositive status to ARC or AIDS. Cuban officials have continually cited these as primary reasons for the isolation policy. This early report also contained an assertion that would be echoed repeatedly in the following months, that few seropositives had in fact become sick, and that this proved the effectiveness of the sanatorium as a care delivery system. It was also evident that although MINSAP officials clearly felt that they were doing the right thing, they did not see their policy as a model for other nations:

These measures are possible in Cuba now because the number of carriers of the virus is minimal. The measure of control taken on time prevented the

number from becoming massive. Unfortunately it has not happened this way in many countries. Others especially in the Third World don't have at their disposal the resources or the technical means to confront the problem effectively.³³

The Cuban policy of separating seropositives from the rest of the population has been described in various ways by various observers. It is commonly referred to as "quarantine" by the U.S. press (including sectors of the left-wing press which are sympathetic to the Cuban revolution.³⁴) Yet Cuban officials tend to avoid the word, preferring the more neutral "isolation" (aislamiento). In fact it is sometimes specifically argued that the arrangement is not a quarantine in the technical epidemiological sense:

seropositives in Cuba are receiving preventive health treatment; they are not quarantined. Since these people visit their families, engage in tourist excursions to various places, and receive visitors, you cannot call this 'quarantine,' as defined in the classic texts on epidemiology.³⁵

Others have attempted to strike a middle ground by describing the policy as a modified quarantine.³⁶

Los Cocos itself, of course, is described in terms as divergent as "a concentration camp"³⁷ and "a resort area... a tropical vacation spot, [with] really nice houses, especially nice by Cuban standards, with color televisions, and air conditioning, and flowering plants all around." ³⁸

There is no purely neutral way to describe the policy and the facilities. Luckily, there is little disagreement about some of the basic workings of the policy. Some of the groundrules are as follows: those confined to the sanatorium are not allowed to work. They are allowed to leave to see their families, but they must obtain special passes to do so. People who live close to Los Cocos go home on Sundays between 8 am and 12 midnight. They have a chaperone. Those who live farther go home every 6 weeks and stay for 5 days. According to several accounts, the leave is commonly extended to longer periods of time.³⁹

Evolution of the policy

In large measure Cuban policy regarding HIV infection remains unchanged since the initial isolation of the first 24 seropositives was implemented in April of 1986.⁴⁰ The fundamental objective and strategy remain intact: prevent transmission via isolation; monitor seroprevalence via broad screening programs (chiefly those returning from abroad, all hospital in-patients, all pregnant women, sexual contacts of seropositives, and residents of selected geographical areas; also all foreign visitors planning to stay more than 3 months). Yet some important events have occurred. There has been a modest loosening of available information. There has been some serious talk of - and perhaps some implementation of - a liberalization of the isolation

policy. Life within the sanatorium has reportedly been improved, with increased opportunities for work and study.⁴¹ A second isolation facility has been opened (in Sancti Spíritus) and a third is planned, for Santiago de Cuba.⁴² The additional facilities will help to accommodate the larger number of seropositives and will allow people to remain closer to their homes. And of course the numbers have grown. At the end of 1989, having tested over half of all Cubans and 75% of the sexually active population, the seropositive caseload had grown to 356. In December of 1989, Los Cocos had a total of 298 residents.⁴³

Demographics

Who are these 356 people? Who is at risk for HIV infection in Cuba? The initial suspicion of the health planners, that the internationalist community was a major high-risk group, appears to have turned out to be correct. According to Cuban government sources, almost all seropositive cases have been linked to sexual contact with foreigners, sexual contact outside the country, or to sexual contact with a Cuban who had been infected in this way. Of course this definition of a risk group seems to follow the same old script which blames the outsider(s) - nonetheless it appears to have some epidemiological value in Cuba. In the early months of the screening program, a major effort was made to track down the many thousands of

internationalists who had served in recent years as soldiers, doctors, teachers, etc., all over the world.⁴⁴

Actually much of the blaming and politicking that happens in discussions of the demographics of the Cuban seropositive community focuses on the question of which internationalists we are talking about. Cuban officials were quite willing to point out that the first man to die of AIDS in Cuba was a theater producer who had spent time in New York in connection with his work. (At one point early in the epidemic, Dr. Terry of MINSAP even stated that "virtually all the cases we've had are linked to sexual transmission of the disease by foreigners from capitalist countries."⁴⁵) But Cubans have strenuously resisted efforts to describe the Cuban military presence in Angola as a significant source of infection. Anti-Castro Cubans in Miami and elsewhere, meanwhile, have been vociferous in their assertion that Cuba's African foreign policy has led to widespread infection (even going so far as to blame the presence of AIDS in the United States on Cubans who got infected in Africa, then brought the disease to the U.S. during the Mariel boatlift of 1980. Given what is known about the long incubation period of the virus, the absurdity of this claim will not be lost on the thoughtful reader.⁴⁶) The best available statistics attribute approximately a third of the seropositive caseload directly to sexual contact in Africa.

The ratio of men to women among seropositives in Cuba is approximately 2.7 to 1.⁴⁷ It was initially higher, but has dropped somewhat, which is evidence that the relative importance of heterosexual transmission has risen. Approximately a third of the male seropositives are gay or bisexual. Almost all of the infections are attributed to sexual contact. The following table gives a breakdown of seropositives by risk factor through the end of 1988:

Table I -- Risk behaviors among Cuban seropositives⁴⁸

<u>Risk Activity</u>	<u>No.</u>	<u>%</u>
sex outside the country	122	45.6
sex with a foreigner inside Cuba	17	6.3
sex with someone in 1 of the above groups	99	36.9
received blood transfusion	3	1.1
hemophiliac	2	0.7
child of infected parents	1	0.4
occupational exposure outside Cuba	1	0.4
unknown risk factor	<u>23</u>	<u>8.6</u>
TOTAL	268	100.0

As can be seen from the table, parenteral transmission of HIV is almost non-existent in Cuba. The three cases of infection through blood or blood products all occurred before universal screening of blood was implemented in 1986. (It is often ironically noted by Cuban health officials that

the U.S. economic blockade against Cuba protected their hemophiliacs and other recipients of blood products from becoming infected during the early 80's.) The virtual elimination of parenteral transmission in Cuba is a laudable accomplishment for a poor country and has received widespread praise.⁴⁹ Once the blood supply was protected, parenteral risks essentially disappeared, since there is very little use of recreational injection drugs (many sources claim that the phenomenon simply does not exist at all in Cuba).⁵⁰

The table also shows that there is one case of vertical transmission. So far this has not been a major problem in Cuba. Abortion is legal and is socially accepted; pregnant women who are HIV+ are reportedly encouraged but not forced to undergo therapeutic abortions. A recent report in Granma, however, noted that two of the women residents of Los Cocos are pregnant.⁵¹

The attached tables summarize some of the relevant seroprevalence and demographic information available through the end of 1989.

 Table II - seroprevalence, cases and deaths from AIDS,
 1986-1989⁵²

<u>Date</u>	<u># tests</u> ¹	<u># positive</u>	<u>cases</u> ²	<u>deaths</u>
Apr. '86	*	24	1	1
Mar. '87	700,000	108	3	3
Sep. '87	1,100,000	147	4	4
Dec. '87	1,500,000	168	24	5
Feb. '88	1,600,000	190	27	6
May '88	2,200,000	227	33	8
Nov. '88	*	270	40	11
Feb. '89	3,400,000	275	51	13
May '89	4,300,000	297	61	16
Nov. '89	5,500,000	356	63	17

1 cumulative; rounded to nearest 100,000

2 CDC clinical classification IV

* data unavailable

 Table III - demographics of Los Cocos residents at selected
 dates⁵³

<u>Date</u>	<u>Men</u> ¹	<u>gay/bi</u> ²	<u>str</u> ²	<u>Women</u>	<u>par.</u> ³	<u>child</u>	<u>Total</u>
Sep. '87	111	32	79	31	*	*	142
Feb. '88	144	*	*	40	5	*	184
May. '89	200	72	128	81	5	1	281
Dec. '89	218	81	137	80	*	1	298

1 total male residents; 2 male only; 3 parenteral

* data unavailable

Education

The quality and effectiveness of the Cuban AIDS education plan has been a sticky point throughout the history of the policy. Especially early on - say, in 1986, 1987 - the official account was that widespread, straightforward, and honest education has been one of the pillars of the Cuban plan from the start. And there is certainly evidence to bolster this claim. Upon visiting Cuba it is not difficult to run across AIDS education posters in health facilities or schools. The most common type observed by the author attempt to dispel myths about casual transmission. Similar messages were appearing in Granma certainly as early as 1986, if not before.⁵⁴ These educational materials are sometimes somewhat dry and technical, but the information presented is accurate.

Supporting the view that AIDS educational outreach has been effective is the following account by a Havana high school student:

For example in my high school they've had at least two conferences in the past school year about AIDS and how it's transmitted, and how many people have it, just the facts about what's going on in Cuba in terms of AIDS and what's going on in the rest of the world in terms of AIDS... They have sex education just on a normal basis in schools all over the place. Young people are really getting motivated about safe sex. [And young people] are really mostly informed about what's going on in terms of AIDS.⁵⁵

Early on, the methods of public education included meetings at workplaces, health education through the clinics, and conferences for workers and students. Use of the mass media came later, but included several television programs that were reportedly widely viewed.⁵⁶

However, it has also frequently been charged that the Cuban government's reliance on a policy of mass screening and isolation has led to education being put on the back burner - or even worse, that isolation policy has itself encouraged irrational and hysterical attitudes, such as fears of casual contagion. [If they are locked up, it must be because the general public has something to fear from their running around loose - right?] Evidence of such attitudes was unfortunately easy to uncover in candid interviews with health authorities. One doctor commented,

it is my experience that if you tell anybody, even a physician, that a person has SIDA - AIDS - everybody's afraid. He is afraid to get in touch with the people, he is afraid to touch the people because they always says "well - as far as you know this disease is not spread by this sort of way. But how you can insure me that I cannot be infected?" And this is habit... Everyone is afraid to take any chances.

Q: Do some doctors refuse to deal with patients with AIDS?

A: If I am going to be sincere with you I have to say yes. That's happened all around. So yes... [If] you know about the disease, you know that you have not to be afraid. But as long as you don't know, it happens... I can tell you for example that the other day I get a

patient who has AIDS who is homosexual; I saw him and then I gave him a lift in my car. So he was going over to his home. I said, I can bring you over to your home. So he entered my car and sat down in the front seat. And then I saw also a computer girl that works here, she's an engineer, and then I took her also on the lift. And then I start talking with the guy, and well, in the conversation I spoke with him, something about the patient with AIDS... So she knew that he was infected with AIDS. And then she said immediately, "you should stop here, I am going to go out of the car; I should never be in your car again." And I said, "don't be so afraid, that is something that do not walk, you know? I put here my child. There shouldn't be any problem." But that's how the people feel. And that doesn't mean that everyone is going to have the same behavior, but that is something that happens.⁵⁷

It has been officially recognized that the education policy is inadequate. Dr. Hector Terry, vice-minister of public health, for example, commented in interviews during 1988 and 1989 that the educational campaigns had been weak and ineffective. However, he rejected the assertion that the isolation policy has skewed Cuban planners away from the necessary educational efforts.⁵⁸

One could spend a lot of time arguing back and forth about whether a sincere educational effort has been made. Probably the more important point, however, is to ask whether the social conditions under which the educational program is being carried out are conducive to success. In other words, do they have the basic tools to make an

educational campaign work? Are they moving in the right direction? Or are there structural stumbling blocks to an effective AIDS educational campaign in Cuba?

One such stumbling block has already been alluded to: the contradictory message inherent in isolating seropositives while claiming that casual transmission is impossible. Of course Cuban planners are not unaware of the facts about AIDS. They do not isolate seropositives because they fear casual transmission. They know how HIV is transmitted, and in quarantining seropositives they have set out very deliberately to control their sexual behavior. But the subtleties of this distinction (probably more than the embarrassment of explaining that people are being locked up to make sure that they do not have sex) is undoubtedly lost on much of the population. So in a sense one end of their strategy is inevitably unraveling the other end.

But there may be other structural obstacles to effective education. One key point is brought out by Susan Laver in her essay "African Communities in the Struggle Against AIDS: The Need for a new approach." The piece discusses the African experience with education, but brings up several important issues which may be relevant in the Cuban case. Specifically, she argues that there have been several problems with heavy reliance on a top-down approach employing the mass media. She quotes several studies that show that a variety of problems have impeded the

effectiveness of this method, and argues for a new participatory approach:

meaningful and enduring changes in behavior can only be achieved individually or collectively if increased opportunities are created (and subsequently provided) for communities to enter more actively into the broader issues of the AIDS debate, i.e. its detrimental effect upon society and development... [there is a] need to shift away from prescriptive traditions of information giving, which seem to characterise AIDS campaigns, and move more rapidly towards information sharing. It is ... essential that we wean Health Workers, and indeed the public, from a dependency on mass media as the panacea for AIDS education, and encourage instead, the adoption of educational approaches which activate dialogue, generate information exchange and permit greater participation by lay people and all levels of Health Worker.⁵⁹

But participation at the most basic level in the planning and execution of AIDS education is exactly what is lacking in the Cuban AIDS education program, which is planned and administered, like so many things in Cuban society, via a centralized national agency.

It is perhaps a reflection of this lack of participatory democracy in the Cuban AIDS education program that a strange illogic or incongruence appears when the entire Cuban AIDS program is considered. On the one hand, the isolation policy is justified in part by reference to the difficulty of profoundly changing people's sexual behavior (admittedly a difficult task). Thus observers

sympathetic with the Cuban plan have repeatedly insisted that one of the reasons that the sanatorium is necessary is that promiscuity is SUCH a well-established and seemingly ineradicable tradition, among Cuban men.⁶⁰ Yet on the other hand, the educational messages lay a heavy emphasis on telling people to not be so promiscuous. In place of insisting on condom use, there is a strong normative message to stick to one partner. This is seemingly somewhat contradictory or at least is evidence of the insincerity or lack of faith/confidence (on the part of those running the educational campaign) - in their own work.

Coercion

How much coercion has been used in the implementation of the Cuban AIDS program? Like so many other aspects of the policy, this question has been hotly debated. Right-wing critics of Cuba have widely circulated their vivid and disturbing version of the quarantine process:

Those who test positive are asked to go voluntarily to a special isolation facility. If they refuse, a special police unit brings them in by force, throwing over their heads a nylon bag with holes cut only for the eyes and nose before carrying them to the police car.⁶¹

At the opposite extreme, advocates of the Cuban policy have frequently claimed that no coercion is ever used, and that the policy is entirely voluntary. In support of this

position is the oft-quoted case of the woman in Pinar del Rio who tested positive but refused to go the sanatorium because she had no relatives to care for her four small children. This example is frequently cited as proof that in fact no one is forced to relocate to Los Cocos.⁶²

(There is something invidious about the way this woman's case is invoked. She is invariably described in purely altruistic, maternal terms -- as if to imply that she is a paragon of moral purity, therefore a low risk to others, and undoubtedly at the opposite extreme in terms of sexual behavior from the typical promiscuous Cuban heterosexual man, or, worse yet, the typical promiscuous Cuban gay man. Nonetheless, it must be recognized that her case does illustrate at least some degree of flexibility in the process of relocating seropositive individuals.)

How can these varying accounts be evaluated? Unfortunately it is extremely difficult to do so by visiting Cuba and speaking with government officials or others. Cuban doctors and government representatives have an interest in portraying their health care system as beneficent. If there were any truth to the highly critical accounts of coercive relocation, they would be extremely reluctant to admit it, especially to a visitor from the U.S. Thus it is necessary to rely on the strength of the arguments presented.

One U.S. citizen who is a journalist and long-time

resident of Cuba argues that the disturbing accounts of people being dragged from their houses with bags over their heads could not have happened, for the simple reason that in a country like Cuba, there would be no way to keep such events secret:

Cuba is a very small-town society. There is no possibility whatsoever that something like that could happen in Cuba and not have everybody talking about it the next day... It simply never happened. I have asked all of my gay friends, I've asked the people in the sanatorium. [And] even if I didn't have friends who were gay, if I didn't have friends who were in the sanatorium and knew people in the sanatorium, if I didn't have a number of other contacts, my next-door neighbor would have told me the next day. I can absolutely guarantee you. It's not the kind of thing that you wouldn't hear about.⁶³

This is a convincing personal testimony. But even if the brutal image of people being dragged from their homes does not accurately represent reality, other more subtle kinds of coercion - including threats of more stringent methods - must be considered as possibilities. And there is substantial reason to believe that more subtle methods of coercion are indeed employed.

In a widely quoted piece published in the New England Journal of Medicine, Ronald Bayer and Cheryl Heaton consider the question of coercion and conclude that although much remains uncertain, "it is doubtful that a potentially lifelong quarantine could be sustained if it were widely

known that the refusal to cooperate would be greeted passively."⁶⁴ This is logical enough, although it might be noted that the authors assume that in general, no one would want to move to the sanatorium given an alternative choice of remaining in the community, which might not be universally true among Los Cocos residents. At any rate, the fundamental argument is probably correct - some degree of coercion is undoubtedly an essential part of the policy of isolation.

Various factors probably contribute to the pressures which convince people to go to Los Cocos. A team of medical personnel is assigned to convince the person to go to the sanatorium, and doctors have great social authority in Cuba. People are told that the move is necessary to protect their health, that their families' needs will be taken care of, and that they will receive their full salaries while inside the isolation facility. These "positive" pressures - carrots, if you will, may very well appear compelling. But surely the converse suggestions are not far beneath the surface - that if the person does not cooperate such resources will not be made available. The threat of losing one's job might also be used as a none-too-subtle form of pressure; after all, those who are relocated are in general not permitted to keep their old jobs.

If medical personnel are unable to convince the person, family and friends are enlisted to help in the persuasion,

according to health officials.⁶⁵ The fact that a person's social support network might be enlisted in such a manner raises another important point which may contribute to the reasons people go to Los Cocos. As a general rule, the isolation policy appears to be commonly accepted by many ordinary Cubans (of all sexual orientations). In this context, it becomes increasingly difficult to imagine opposing it on an individual level. Specifically, a seropositive person in the community might very well face an uphill battle against ostracism if her seropositivity became general knowledge.

In the final analysis, the balance of power is heavily on the side of those doing the persuasion. And in fact the compulsory nature of the internment has been acknowledged in recent accounts in Granma.⁶⁶ Ultimately then, there is little doubt that people are compelled to enter the isolation facilities. However, there is reason to believe that the least violent alternative is generally employed as a method to compel the relocation. What remains to be considered is how seropositive individuals actually feel about the process and whether they offer any level of cooperation with the policy. This question will be considered further in the next chapter.

IV. SEEKING EXPLANATIONS: THE POLITICAL AND CULTURAL ROOTS OF CUBAN AIDS POLICIES

Cuba is a country which boasts of having a model health care service. Since the mid 70's democratic structures ('poder popular') have been supposedly effecting more popular participation and input into the functioning of the health care system. Furthermore, the health care system has continued to change in ways which appear to respond to local demands and to improve quality of care - witness the family doctor program. So why does Cuba have an AIDS policy which is contrary to the recommendations of the WHO and which violates the civil liberties of its citizens? This chapter will examine this question, focussing particularly on the issue of quarantine of seropositives.

For the good of the people?

There are many possible explanations for Cuba's AIDS policies. To begin this discussion one might first ask whether the justifications given by the government, (which appeal to the good of all and the scientific necessity of quarantine) are sufficient. Certainly Cuban health officials sincerely wish to control the spread of AIDS. For one thing, the consequences of an AIDS epidemic in Cuba would be a fiscal as well as a human disaster, since all health care is provided free of charge by the state. In addition there is every reason to believe that Cuban health policy is

motivated in part by a sincere commitment to preserving and promoting the health of all Cubans. Could Cuba's AIDS policies be seen as an overreaction based on fundamentally good motivations, a mistake driven by overprotectiveness?

This explanation is compelling - the more so following extended discussions with Cuban doctors and epidemiologists, many of whom are undeniably dedicated to serving their people and providing the best for them. Furthermore, many of these health workers and health officials are clearly convinced that their strategy will work. Yet some questions remain. Harsh AIDS prevention measures like Cuba's are almost universally rejected by international health policy planners - on pragmatic, scientific, and ethical grounds; why were these recommendations overruled in Cuba? For example, was there no concern that the policy would backfire by driving seropositives underground (as is so often predicted in international literature which condemns coercive testing or isolation practices)? Cuban health officials claim that the sanatorium was set up for the good of the seropositives as much as for the good of the rest of the population, but this is hard to believe. It takes no special genius to guess that such treatment might have debilitating psychological (and perhaps somatic) consequences for the seropositives, regardless of the physical conditions of the sanatorium. And there is no logic at all to the claim that longitudinal study and

thorough medical care of seropositives would be impossible if quarantine were not imposed. So although some Cuban health officials may be sincerely motivated to help their people, it may be worth considering other explanations of the policies.

To harm the people?

What about the converse of this first explanation? According to the right-wing critics, AIDS policy in Cuba is just another of a long series of totalitarian acts carried out by a repressive government. From this perspective the policy is easy to explain. Is this view sufficient?

There are several problems with this explanation as well. For one thing, it is somewhat illogical. Why would Cuba invite so much criticism, (including from some of its usual fans, such as the U.S. left) merely to be cruel to its seropositives? And why would Cuba purposefully alienate a segment of its population - even a small segment - if there is no medical or scientific reason to do so? Furthermore, this conservative viewpoint is absurdly one-sided. It ignores the fact that there are indeed aspects of Cuban health care which are effective and benevolent. Surely there are more satisfying explanations for Cuba's AIDS policies.

Ideology

A third explanation which comes to mind is in some sense similar to the second. Cuba may not be a totalitarian dictatorship (and its policies may not be universally cruel and authoritarian) but it is certainly a centrally-planned society based on a socialist ideology, in which the national government has a great deal of power. [Even very sympathetic researchers such as Vicente Navarro acknowledge that popular participation in health care in Cuba has been largely limited to the implementation of policies planned at the national level.⁶⁷] Could Cuba's AIDS policies be explained by reference to a socialist ideology which is inclined towards collective solutions rather than individual solutions to health risks?

This explanation may have some validity but it also has some flaws. The national government clearly has a great deal of power to control the lives of Cuban citizens; the policy would not be possible were this not so. However, it is difficult to make an immediate leap from socialist ideology to a specific health policy; that is, it is not clear that ideology determines policy.

In a fascinating analysis of the prevention of chronic disease in Cuba, Sylvia Tesh argues that Cubans have an individualistic view of health and illness:

when Cubans report on health (see any of Castro's speeches to the people) they describe medical services, not the broad social actions that [the foregoing

discussion] implies are responsible for improvements in morbidity and mortality... Such a stance reflects and implicitly perpetuates a mechanical model of health and disease and thus individualizes illness.⁶⁸

Tesh goes on to show that Cuba's major prevention programs aimed at chronic illness place the responsibility for disease prevention on the shoulders of individuals. Cubans are exhorted, for example, to exercise more, to stop smoking, to change their diet. But little effort is made to address the underlying structural reasons that Cubans might not exercise or eat well. Instead of sports programs in the workplace, people are told that it is their individual responsibility to exercise more. Tesh argues that this reveals a failure to base health policy on sound Marxist principles, namely, that "health behaviors are a reflection of underlying economic institutions and cannot be effectively changed without changing the mode of production that produced them."⁶⁹

It is clear from Tesh's analysis that health policy in Cuba does not arise in any simplistic sense directly from the ideology espoused by the government. So an appeal to socialist ideology as an explanation for Cuba's AIDS policies is thrown into doubt. Why should this particular health policy be based on ideology more than any other health policy? Another problem with the "ideology" explanation is that not all observers would agree that Cuba's AIDS policies are indeed socialist in nature. In

fact one might make the argument that in effectively punishing seropositives for their antibody status, the Cuban government is implicitly taking a stance which blames individual seropositives for the presence of the disease on the island.

At this point in the analysis the reader will be asking: what would be a true Marxist approach to the prevention of AIDS? The answer is difficult, since AIDS differs in some important ways from the diseases usually discussed by leftist health policy analysts. It is often stated that sickness is a result of underlying economic and social causes; thus, the world's infectious disease burden is largely a result of poverty; the chronic degenerative diseases which are major killers in the U.S. are a result of our sedentary lifestyle or the stress of urban society. A good Marxist approach to these diseases is of course to change the underlying causes which are rooted in the mode of production of the societies involved. Now what about AIDS? What is the underlying social and economic cause of this deadly disease? I would contend that AIDS is not primarily a result of the social/economic conditions of the developed world, nor a result of the poverty of the underdeveloped world (though it is strongly linked to poverty in both developed and developing countries) - but rather a random act of malevolence on the part of the biosphere.⁷⁰ This is not to argue that poverty, drug abuse and unsafe sex should

be continued, but merely to point out that assigning blame and planning prevention on the basis of structural factors is complex in the case of AIDS.

Homophobia

A fourth explanation for Cuban AIDS policy assigns the blame to Cuban culture. Specifically, it is frequently pointed out that Cuban society suffers from a great deal of homophobia. Thus for example there was a brief time in the 60's when Cuban gays were rounded up and sent to work camps. While this is no longer done, Cuba remains an uncomfortable place to be gay. Is this the reason for the quarantine policy?

Homophobia in Cuba is widespread, and may very well have influenced the thinking of Cuban health planners in the early years of the epidemic. However, there are several reasons to doubt that it is the key explanation for Cuba's stringent AIDS policies. For one thing, the country as a whole appears to have avoided a return to the extreme homophobia of the 60's. Thus members of the gay community in Havana who were interviewed in 1987 by the Guardian "report no increase in homophobia or attacks on gays as a result of AIDS."⁷¹ Furthermore, they reportedly "attribute this in part to the fact that the government has not singled out gays as carriers of the disease."⁷²

One simple reason that gay people have not been

strongly identified as a major risk group in Cuba is that the demographics of HIV infection in Cuba reveal a relatively major role for heterosexual transmission. Gay or bisexual men make up only about a third of the male population at Los Cocos, and the male:female ratio among seropositives has dropped over the past two years. Also, if many of Cuba's seropositives were infected while stationed in Angola (as is often asserted), then heterosexual transmission may indeed be the major concern for Cuban health planners. (And official figures do put the number of Cubans infected in Africa higher than the number of men infected via gay sex.⁷³) Thus it is no surprise that Cuban AIDS education materials tend to stress the dangers of heterosexual transmission, although homosexual transmission is also discussed.

Furthermore, there is some evidence that recent years have seen an increasing level of acceptance of homosexuality at the highest levels of government. Thus for example, the director of the national group on sexual education has stated explicitly that overcoming homophobia is an important goal:

we are convinced of the need to ensure that our people in a socialist and essentially humanist society accept an ethical and moral principle that is fundamental as far as I'm concerned: we don't have the right to measure or evaluate quality or the condition of some people, some human beings, based on their preference, their desires, their

sexual activities.⁷⁴

Others have pointed to various indications that Cuba is moving towards a more enlightened view of homosexuality. For example, in 1979 an official textbook on sex education was brought from the GDR to Cuba and published in Spanish. This book, entitled The Intimate Life of Man and Woman, described homosexuality as an alternative lifestyle which is not a sickness. The book stops short of fully supporting a gay lifestyle as being as valid as a heterosexual one; numerous stereotypes are reinforced and the tone of the author indicates sympathy for those who are shocked by the idea of homosexual sex. Yet the publication of this book was widely considered a major advance in the acceptance of homosexuality.⁷⁵

Just how hard it is to be homosexual in Cuba has been a topic of much debate in the progressive press in the United States.⁷⁶ One key point of contention is whether there is currently official discrimination against homosexuals. Defenders of Cuba argue that while discrimination clearly exists, it is a reflection of popular beliefs, not government policy. They also argue that such discrimination goes back much further than 1959; that is, it is not primarily the result of the revolution, but of ancient prejudices. However, it must be recognized that government representatives and government publications tend to mirror these popular beliefs.

It remains plainly obvious to an outsider visiting the island that Cuba is a tremendously closeted society. Progress in this arena has been exceedingly slow, due to the legacy of Catholic teachings, the traditional culture of much of rural Cuba, and the negative memories of homosexual prostitution during the Batista times.⁷⁷ Yet what is most striking about the problem of Cuban homophobia during the AIDS years is that the overall trend of extremely slow progress appears to be continuing, largely undeflected by the AIDS epidemic.

In short, although homophobia has undoubtedly contributed to the climate in which policy decisions were made, there are also reasons to doubt that it is the overwhelming factor which has shaped AIDS policy.

Stigma and the island mentality

A closely related issue is the stigma which surrounds AIDS. The disease is irrationally feared worldwide, and those afflicted with it are commonly disdained, often in a vague and sub-rational manner which may be only partly informed by a tradition of homophobic beliefs. In places where transmission is largely heterosexual, for example, stigma may still be a tremendous problem - carrying implications of promiscuity, of prostitution, or of contact with Europeans or Americans.⁷⁸ Thus a fifth explanation for the Cuban policy might be that in spite of a solid

scientific knowledge base on AIDS, Cuban planners are in part reacting out of a queasy, subjective uneasiness, or frank revulsion, towards this "plague of the 20th century."

Cuban officials will deny this charge, of course. They tend to describe their motives as purely rational and stubbornly defend their cloak of scientific objectivity. Yet there is certainly evidence that irrational fears have played a role in decision-making during the AIDS epidemic, and there are clear patterns of official stigmatization of people with AIDS.

One of the most vivid illustrations of this official stigmatization is that in television programs and newspaper articles on Los Cocos over the last two and a half years, the faces of the residents have generally been blacked out. This is to protect their privacy, some have argued, and to protect them from the results of popular prejudices against PWAs. But the seriously deleterious message - a message of shame and the need to hide one's identity - is all too obvious. There is really little excuse for such practices; they demonstrate a very elementary level of consciousness about the dangers of blaming the victim.⁷⁹

Similarly, irrational fears have at times undeniably guided policy decisions. In 1986, a Mariel refugee living in Boston died of AIDS-related causes. His mother had obtained a special visa to travel from Cuba to visit him, but the Cuban government refused to allow her to return with

his body, reportedly citing "health risks."⁸⁰

This last example illustrates that irrational fears can sometimes result in paranoid attempts to protect borders. The fact that Cuba is an island may have facilitated the development of such a mentality, for island nations do tend to see themselves as more isolable than other nations.

In her discussion of the metaphors of AIDS, Susan Sontag points out that the disease frequently serves as "a marker of both individual and social vulnerabilities."⁸¹ On a political level, the epidemic

serves as an ideal projection for First World political paranoia. Not only is the so-called AIDS virus the quintessential invader from the Third World. It can stand for any mythological menace.⁸²

Of course in Third World countries, the menace in these metaphors would take the form of a different sort of invader. Cuba, which has felt under siege from the U.S. for 30 years, is in an ideal position to adopt an exactly inverted metaphor: AIDS as the imperialist invader. Thus we have Dr. Terry of MINSAP claiming in 1987 that "virtually all the cases we've had are linked to sexual transmission of the disease by foreigners from capitalist countries."⁸³

So the fifth explanation for Cuba's policies looks towards deep and unconscious (or semi-conscious) fears of invasion and subversion. If AIDS is viewed as this sort of social threat, then the extreme response of the government

to the epidemic may be seen as an act of group solidarity, or what one writer calls "a social purification ritual."⁸⁴ On this view the policies would have as the main purpose not the maximization of public health, but the strengthening of the sanctity of the highest values of society - in this case, socialism, and perhaps also compulsory heterosexuality.⁸⁵

It is entirely consistent with the evidence to conclude that an unconscious need to respond to deep and unpleasant fears of a mythological (though possibly real) enemy may have contributed substantially to the development of Cuba's AIDS policies.

The biomedical model

There is another possible explanation for Cuban AIDS policy which deserves mention. This sixth explanation looks to the biomedical and doctor-based model which Cubans follow in matters of health care. According to this view, Cubans have simply become much too enamored of science and Western medicine as the answers to all problems. (The quotes from the Tesh article support this view.) Thus, mass testing becomes the only logical solution to finding out the extent of HIV exposure, and a tightly controlled experiment necessitating quarantine of seropositives is the logical approach to studying the course of the virus within human beings. Combined with a centrally-planned society, a

powerful national government, and the fear of a worst-case scenario, this argument may go a long way towards explaining what Cuba has done.

But why is Cuba so enamored of science and Western medicine? Some answers to this question were given in chapter II, in which it was explained that long before 1959, Cuba had a heavily doctor-based health system and a tradition of important advances in biomedical research. This point and several others are made by Ross Danielson, who argues that the roots of the revolutionary health system are to be found in pre-revolutionary Cuba.⁸⁶ Although it may seem far-fetched to blame present-day AIDS policies on events which occurred before the revolution, it is nonetheless reasonable to point out that the particular character of the Cuban medical profession is probably an important factor in the shaping of policy. And this character cannot be explained without reference to the past.

Economics

In her discussion on health risks in Cuba, Sally Guttmacher points to three factors which shape decisions about disease prevention strategies: economic constraints, the level of politicization of the population, and the values of policy makers and political leaders.⁸⁷ This chapter has focussed so far on the third of these categories, perhaps justifiably; in many countries, values

have a tremendous impact on the shaping of AIDS policies. But Guttmacher's other two factors deserve some consideration.

So the seventh explanation for Cuba's AIDS policies is an economic one. Certainly short-term economic constraints do not seem to have played a major role in shaping Cuban AIDS policy. However, long-term cost considerations have probably been significant in the policy planning process. The disastrous financial consequences of a larger epidemic in Cuba have not gone unnoticed by policy planners:

The Cuban program of struggle against AIDS is quite costly - said Dr. Terry - but if we didn't do those tests and if we didn't isolate the carriers with the purpose of cutting the chain of transmission, and if we had, let's say, a thousand clinical cases, how much would it cost us to take care of them? Remember that it has been calculated that in 1991 in the United States AIDS cases will cost \$64 billion. Of that amount, 16 billion will be on medical expenditures, and the rest is what those who are sick will be unable to produce and what it will be necessary to provide for them in the form of social security. Without looking at how extraordinarily humane it is to save the life of a man or to prolong that life in hopes of the possibility of a cure, and to protect at the same time the health of the population, if we reduce the matter to a mere question of pesos and centavos, which would cost more?⁸⁸

These kinds of cost comparisons must have produced very compelling arguments for the present policies at the highest levels of planning.

The reaction of the public

Health policy planners must operate in the real world of human society. Although personal value systems and economic calculations clearly influence policy decisions, planners must also consider the reactions their proposals will elicit from the general public. Furthermore, they may have to balance their own ideas of what needs to happen with proposals initiated by grassroots organizations or other non-governmental groups. Even in societies with few independent political organizations or relatively weak democratic structures, popular reaction to government proposals and popular demands for action may play a major role in the determination of health policy. Along these lines, Guttmacher describes the "the level of politicization and organization of the population" as a key determinant of health policy strategies, in Cuba and elsewhere. Thus the eighth explanation for Cuban HIV policies looks towards the general Cuban population to see what role it has played in this drama.

There are no hard survey data available on the response of the population to Cuba's AIDS policies. But there is strong anecdotal evidence to suggest that there is a surprisingly high level of acquiescence to the policies. For example, the campaigns of HIV testing in selected Cuban towns have reportedly been met with cooperation, for the most part. As Dr. Galbán García of MINSAP explained,

We have been criticized internationally [for having mandatory tests.] But it is necessary to understand the idiosyncrasy of the Cuban people to be able to understand how much we work with the people on health issues. Since 1960 we have had many health campaigns with the Cuban population: campaigns of testing for tuberculosis, of testing for numerous illnesses. And everybody learned to cooperate with this whole system of testing. For example, we recently developed a serologic diagnostic test for leprosy [which shows the presence of the bacillus before there are any clinical manifestations]... and everyone accepted it just fine. Or something as intimate as for example the Pap test, in Cuba it's something commonplace for a health brigadista to knock on the door and say to the woman that she needs to go to the polyclinic to get a Pap test. That sort of thing is ordinary here. Nobody feels less free because someone is thinking of them and asks them to do that. It is for this reason that we were able to develop our studies of the general population.⁸⁹

Even more striking are the indications that the quarantine policy is widely accepted among many ordinary Cubans, including members of the gay community. A source admittedly sympathetic to the Cuban government testifies that many gay men in Havana view the quarantine as a measure necessary to ensure their safety:

Tomás is a very educated person, he is a designer; he worked for the government; he is a revolutionary. He is the kind of person who AIDS education works for. I don't have any doubts that if Tomás were out on the street that Tomás would be completely reliable, that he would use safe sex, that he is not about to infect his partner or anyone else. [But] even Tomás felt ... he wouldn't want to see the majority of the other people that he knew in the sanatorium out on the street. For the same reason that the other gay men who were at Albertico's house didn't

want to see them out on the street. What they said was, 'look, people are very promiscuous; people swap partners very often. And not everybody is very honest. And how are we going to know which ones are and which ones aren't? They're not all like Tomás. We know Tomás, we can trust Tomás. And what about all the others that we couldn't trust?'... The majority of the population, heterosexual and homosexual... feels very strongly that it's up to the ministry of public health to protect them.⁹⁰

Other observers have similarly commented on the remarkably high level of acquiescence among those most closely affected by the isolation policies. A U.S. anthropologist who has traveled to Cuba several times commented,

I think there is an understandable high level of trust that Cubans have in their health system, and in their government. Otherwise I cannot explain a lot of the reaction on the part of the HIV+ people and their friends and families. A kind of trust and acquiescence in a plan which does indeed have one very major ethical, controversial aspect.⁹¹

Even some sources who are extremely unsympathetic with the Cuban revolution have noted the acquiescence of many to the isolation policy. An example would be the section on AIDS in a special bulletin released by the Cuban American National Foundation (an anti-Castro organization). This bulletin allegedly reproduces the "leaked" results of a public survey conducted in 1987 by the Communist Party on the quality of health care in Holguín province; most of the reported opinions are sharply critical of the quality of services. But the section on AIDS is introduced as follows:

With reference to this illness, called the 'Plague of the 20th century,'

favorable opinions indicate a high degree of confidence and satisfaction on the part of the population regarding the measures taken by the Cuban Ministry of Public Health to prevent massive contamination...⁹²

Furthermore, most of the complaints listed in this section consist of calls for more testing of various groups - prisoners, promiscuous people, gays. There are no expressed concerns about the restrictiveness of the policies.⁹³

In a highly critical account of the relocation of a seropositive gay university student, one U.S. journalist made the following observation:

One male student who described himself as homosexual, like Mendoza [the man who was relocated], shrugged and said, 'This is Cuba. What are you going to do, refuse to go? ... It's too bad for him, but he got infected and it's safer for everybody that he go, and it's safer for us (gays).'⁹⁴

Here again is an account by an unsympathetic observer, who nonetheless has documented that among those most closely affected by the policies, there exists the opinion that isolation is necessary to protect the uninfected.

None of these quotations prove that there is universal acceptance of the policies, nor do they comprise a justification for forcible relocation. But they do perhaps allow a reconsideration of some assumptions that most north americans have about the Cuban plan, i.e. that it would be universally experienced as an unjustifiable infringement of individual freedoms. Assumptions about individual and

collective rights and responsibilities and the role of government may indeed differ substantially from one society to the next, and acquiescence to the restrictiveness of Cuba's AIDS policies may in part reflect these different assumptions.

However, the anecdotal data are insufficient to accurately judge the level of acceptance of the policies among seropositive individuals themselves. Of course it has been asserted that some of them accept their internment gladly.⁹⁵ Pro-Cuba accounts tend to describe a range of opinions within Los Cocos, from full acceptance to moderate disagreement. While this recognition of diversity within Los Cocos lends some credibility to the sympathetic reports, the political bias of the authors and the extreme difficulty of verifying the accuracy of the reports renders them suspect.

Still, there may be some reason to entertain the possibility that some seropositives might be in agreement with the government's actions. It has been argued that many of Cuba's seropositives are from the most pro-revolutionary segments of Cuban society, since they were chosen to serve as internacionalistas in foreign countries.⁹⁶ Thus it is argued that the initial instinct of these individuals is to support the government's actions.

The bottom line, however, is that the isolation facilities are closed to foreign journalists, researchers,

and other visitors (though a handful of exceptions have been made). Under these circumstances one can only assume that there is something the government wishes to hide.

Furthermore, there is a fundamental logical flaw in the assertion that a seropositive individual could acquiesce to isolation through a high level of consciousness of his duty to society. If the person fully understands the need to protect others and is willing to do so, then there is no need for isolation; a high level of cooperation and consciousness would obviate any possible scientific justification for quarantine. In other words, if someone freely and willingly gives up her freedom to altruistically protect society, why on earth couldn't she simply give up unsafe sex and accomplish the same goal? The answer, of course, is that there is little official faith that people will behave in a responsible way. So in fact the level of cooperation and commitment to sacrifice for the good of society must be considerably less than what is claimed.

But seropositives are a very small segment of Cuban society. In calculating the political feasibility of the quarantine policy, the opinions of other groups undoubtedly weighed more heavily in the minds of policy planners. And as has been shown, there appears to be widespread support for the drastic measures which have been implemented. Thus the desires of the Cuban people to be protected from HIV infection must be counted as a factor which encouraged the

implementation and continuation of Cuba's extreme strategy for controlling AIDS.

Summary

At this point it will be obvious that numerous factors have probably contributed to the Cuban government's decisions regarding AIDS. The eight which have been proposed here - including ideological, historical, cultural, economic and political considerations - may have all contributed to the policy. However, some of these explanations stand out as particularly compelling: fear of subversion; the island mentality; excessive faith in a positivist, biomedical model of aggressive public health measures; the acquiescence of the public; and a determination on the part of planners to protect the health of Cubans and save the country from financial ruin.

It is notable that the motivation which most clearly emerges in interviews with Cuban health officials is that they believed the strategy would work -- and they claim that it already has worked. Are they correct? This question will be systematically explored later (chapter VI).

But before subjecting Cuba's record to meticulous scrutiny, one might ask the question: are the Cubans really so different from everybody else? How are other nations comparable to Cuba confronting AIDS? These questions will be examined in the next chapter, which steps back from the

specifics of the Cuban situation to take a generalized look at AIDS epidemiology and AIDS legislation on a global level.

V. THE GLOBAL AIDS EPIDEMIC: CUBA IN THE WORLD SETTING

Effective control of any epidemic requires a thorough epidemiological base of knowledge. And it has turned out that AIDS affects and is profoundly affected by international interchange of every variety. Therefore, it is imperative that the nations of the world, as members of an international community, understand not just their own domestic patterns of prevalence and spread of HIV, but the international patterns as well.

This chapter will consider some of the major worldwide trends in HIV disease, with a goal of understanding how Cuba does or does not fit these general trends. First, global epidemiological patterns will be considered. What group of countries forms the most appropriate epidemiological comparison for Cuba? Then, we will look in a general way at the world's responses to the AIDS epidemic. Cuba has been judged harshly for its AIDS policies; but is Cuba alone in employing repressive legislation to control AIDS?

Three patterns

Much of the early literature on the international AIDS situation divides the world into three patterns, imaginatively named patterns I, II and III.⁹⁷ Pattern I countries include the United States, Western Europe, Australia, New Zealand, and South Africa.⁹⁸ Latin America was also initially designated a pattern I area. In pattern

I countries the epidemic started fairly early (mid-70's or early 80's). Transmission is predominantly among homosexual and bisexual men and IV drug users. Parenteral transmission by routes other than illegal IV drugs has been largely controlled through the screening of donated blood and tissues and the use of aseptic technique in medical practice. Perinatal transmission is relatively uncommon, but is an increasing problem among IVDUs, female sexual partners of IVDUs, and in a few other high-risk groups. The male:female ratio is high (estimated to be 10:1 on average). Overall seroprevalence is less than 1%.

In pattern II countries (sub-Saharan Africa and parts of the Caribbean), the situation is quite different. As in pattern I countries, the epidemic started fairly early -late 70's or earlier - but the groups at risk and the demographic trends are quite unlike those of pattern I countries. Transmission is predominantly heterosexual, and the male:female case ratio is 1:1. Because of the large number of infected women, perinatal transmission is a major problem in areas of high prevalence. Parenteral transmission occurs mostly via blood, blood products, the use of unsterile needles in therapeutic settings, and possibly via other skin-piercing equipment. Illegal use of IV drugs is not a major route of parenteral transmission. The overall seroprevalence rate is greater than 1%.

Pattern III countries include most of Asia, the Middle

East, Eastern Europe, and much of the Pacific. AIDS came late to pattern III countries, first appearing in the early to mid-1980's. Population seroprevalence is generally very low in these countries. Parenteral, homosexual and heterosexual transmission have all been documented, but the predominant modes of transmission have not necessarily been established. Until very recently, transmission of HIV in pattern III countries has been linked to foreign contact. For example a 1988 overview of global epidemiology stated that parenteral transmission in pattern III countries occurred mostly in "recipients of imported blood or blood products."⁹⁹ Similarly, cases of infection via sex were thought to have "generally occurred in people who have traveled to pattern I or pattern II areas and who have had sexual contact with individuals from such areas."¹⁰⁰

The changing picture; four patterns

Recent studies have noted that these three patterns are no longer sufficient to fully describe the global AIDS epidemic. Important changes have occurred within each region. In many pattern III countries, HIV has recently established extensive domestic spread within particular communities. For example, HIV prevalence among IV drug users in Thailand and Burma has risen quite rapidly in the past two years.¹⁰¹ In the USSR, unsterilized medical equipment has been linked to recent clusters of HIV

infection.¹⁰²

Major changes in pattern I areas such as the U.S. and Europe include a declining rate of transmission among homosexual men, and a relative rise in the importance of IV drug use as a mode of transmission. There has also been a notable increase in incidence and prevalence among economically disadvantaged groups, especially ethnic minorities in the United States. However, the high male:female ratio in (northern) pattern I countries has not dropped substantially.

Another important trend is that Latin America has diverged from other pattern I areas and is now classified as having a separate epidemiological pattern - somewhat awkwardly designated pattern I/II to indicate that it shares characteristics of pattern I and of pattern II areas. In the pattern I/II region, extensive spread generally occurred in the late 70's and early 80's. Initially, the burden of infection was mostly confined to gay men, IV drug users and recipients of contaminated blood products, but in the middle to late 80's, heterosexual transmission increased dramatically and is now considered the predominant mode of transmission overall.¹⁰³ Consequently, the male-to-female ratio has dropped in this region as a whole. In some pattern I/II countries, this ratio is close to 1:1. Because of these changes, perinatal transmission has become more common and is expected to increase.

The danger of infection through blood and blood products is variable in the pattern I/II region. Some countries have taken important steps to protect their blood supplies, but progress has often been slow because of cost constraints and other obstacles. For example, in 1986 Mexico passed a law requiring universal blood screening, but screening equipment was not in place in many laboratories until February or March of 1987.¹⁰⁴ Even after much of the equipment was obtained, the problem of transmission via blood continued. In June of 1987, the Mexican government decided to prohibit all purchasing and selling of blood after it was discovered that an extraordinarily high percentage of blood samples from private banks were contaminated.¹⁰⁵ Brazil has had similar problems; in 1987 screening of blood was made mandatory, but after the law was passed numerous illegal blood banks continued to operate without such screening.¹⁰⁶

Cuba in the world setting

Where does Cuba fit within these dynamic global patterns? Is it a pattern I/II country, like the rest of Latin America? Parts of the Caribbean have traditionally been considered pattern II; does Cuba fit this pattern? Or is Cuba a pattern III country, like most of what has been thought of as the Soviet bloc or the socialist world?

I will argue that Cuba is something of an oddball

country, sharing characteristics of several of the global patterns discussed. One consequence of this is that comparisons of Cuba with its neighbors or its allies becomes somewhat complex.

Cuba shares with the pattern I region the triumph of having largely solved the problem of HIV transmission through blood and blood products. However, Cuba is also essentially free of illegal IV drug use, like some of the pattern II countries.

Recent papers on the international epidemiology of AIDS have classified Cuba as a pattern I/II country, and in many ways this makes sense.¹⁰⁷ Cuba is certainly grouped culturally and geographically with the rest of Latin America. Furthermore, the male:female seroprevalence ratio in Cuba is approximately 2.7:1; thus Cuba has neither the very high male:female case ratio of a pattern I country, nor the 1:1 ratio typical of a pattern II country. In this sense Cuba certainly appears to be between patterns I and II in terms of the importance of heterosexual transmission. However, in other pattern I/II countries, there has been a dramatic rise in the importance of heterosexual transmission. For example, in Trinidad and Tobago infections attributable to heterosexual contact jumped from none during 1983 and 1984, to 13%, 25%, and 47% in the middle of 1985, 1986 and 1987, respectively.¹⁰⁸ In Cuba, by contrast, the rate of infections attributed to heterosexual

contact has remained fairly steady at about 75% over the two year period from 1987 through 1989.

In other ways one could argue that Cuba most closely resembles a pattern III country. AIDS appeared to arrive fairly late to Cuba (first case reported in 1986), and as in other pattern III countries, most of the infections in the first few years of the epidemic were directly or indirectly attributable to contact with foreigners. However, the risk-group categories in Cuba became established fairly readily, and unlike many pattern III countries, Cuba has shown no recent trends of rapid parenteral or prostitution-associated spread.

In short, it is clear that established categories of global epidemiological patterns have only limited application in the evaluation of the Cuban case. This adds to the difficulty of dissecting the Cuban experience, but it also highlights the importance of considering the unique characteristics of any nation which is struggling to control AIDS.

Repressive legislation worldwide

Cuba is not unique in its attempt to control HIV infection via repressive legislation. Numerous other nations, provinces and local jurisdictions have passed a variety of liberty-restricting laws in an attempt to control the spread of AIDS. This section will briefly review some

trends in AIDS legislation and will compare Cuba's approaches to these trends.

Repressive national legislation regarding HIV and AIDS generally falls into 3 categories: restriction of entry for foreigners with HIV infection or AIDS, various kinds of mandatory screening policies for citizens, and legislation requiring isolation or quarantine. As we have seen, Cuba has laws which fall into all three categories.

However, Cuba is by no means alone in having such legislation. Many countries and smaller jurisdictions have established laws which restrict entry or which require some sort of mandatory screening. There are also some countries besides Cuba which have quarantine or isolation policies, although these have generally been either selectively applied, or designed specifically for recalcitrant individuals who knowingly infect others. Proposals to isolate all HIV seropositives (or PWAs) have not been implemented, except in Cuba, but they have frequently been proposed and debated in numerous places, and have by no means disappeared from the AIDS political debate.

Perhaps the most common of the three types of repressive legislation is entry restrictions. A survey of nations in 1988 revealed 34 which had established or were considering establishing some sort of entry restrictions based on HIV antibody status or a diagnosis of AIDS.¹⁰⁹ These countries span the political spectrum; included on the

list are Belgium, China, West Germany, Iraq, Israel, Libya, South Africa, the Soviet Union and the United States. Many of the countries exempt tourists or those who would be staying only briefly from the requirement, but the length of stay permitted before the test becomes mandatory ranges from five days (Iraq) to one year (China). Some countries (Indonesia, Thailand) specifically exclude those with an AIDS diagnosis, but do not require visitors to get an HIV antibody test. In several countries the testing requirements vary depending on the country of origin of the visitor. For example, Cyprus requires the test specifically for students from African countries. In the state of Bavaria in West Germany, all foreigners applying for residency are required to undergo testing, except for nationals of Western European countries. The illogical nature of many of these specifications is evident.

Mandatory testing policies, like entry restrictions, are not restricted to countries of any particular political conviction. Panama, Sweden, Bulgaria, Jamaica, South Korea, and Iceland are a few of the many countries which have imposed some sorts of mandatory testing on one or more groups of citizens.¹¹⁰ Rarely does such testing encompass universal screening of the entire population, but a few countries do have such broad-scale plans; Bulgaria, for example, had a plan as of 1988 to test all of its citizens by the year 1990. Some countries specifically target some

of the same categories of people that are targeted for testing in Cuba; for example, Iraq tests all of citizens returning from abroad. Frequently, the mandatory tests are imposed on those with little social status; for example, in Guatemala, Panama, South Korea, Austria and Israel, prostitutes must be tested on a regular basis, usually every three or six months. In Austria, prostitutes who test positive have their licenses revoked, but are permitted to then apply for state pension funds. Mandatory screening in the United States has been applied to military recruits and those seeking marriage licenses in particular states.

WHO recommendations and the international consensus

I have argued that all countries have unique characteristics and circumstances which necessitate individually designed approaches to stopping AIDS. Does the necessity for sensitivity to individual circumstances justify any of the kinds of legislation that have been discussed here?

For example, it has been shown that in many pattern III countries, the few cases of AIDS which exist have all or almost all been linked to some sort of contact with foreigners. It might be argued that restriction of entry of HIV-positive individuals is a logical measure for such countries, even though such restrictions have been rejected by the WHO. Can such a position be justified?

I will argue that as a general rule the answer is no. It is true that every nation has complex and individual epidemiological circumstances. Nevertheless there are several reasons to support the idea that the WHO consensus statements on AIDS prevention are indeed appropriate for, and ought to be followed by, all nations.

But to back up for a moment, let us take a very brief look at some of the WHO consensus statements on AIDS and how they came about.

The early response of the WHO to the AIDS pandemic has been described as "embarrassingly slow."¹¹ WHO first formed its AIDS task force, initially named the Special Program on AIDS (SPA), in February of 1987. Later, the name was changed to the Global Program on AIDS (GPA). After its slow start, however, the WHO proceeded to take a major role in facilitating international dialogue on AIDS and AIDS prevention. Under the determined leadership of Jonathan Mann (director of the GPA until very recently), the work of the GPA has grown rapidly. This work includes tracking the spread of the disease, visiting member nations to assist them in setting up AIDS control programs, bringing together experts of various disciplines to draft policy statements on AIDS prevention, and sponsoring AIDS-related research.

Another important project of the GPA has been to sponsor numerous international meetings on the global impact of AIDS. One large and important meeting was held in London

in March of 1988; health ministers and delegates from 148 countries attended. WHO's initial position on non-discrimination and the avoidance of stigmatization of people with AIDS was affirmed by the delegates at this meeting.¹¹² Resolutions on AIDS have also been established at meetings of the World Health Assembly, which is the prime governing body of the WHO (comprised of representatives of all the member states).¹¹³

Thus, the WHO consensus statements on AIDS are partly a result of the work of ethicists, scientists, and other experts brought together by the WHO to work on such statements, but they are also the result of international discussion, collaboration, and democratic decision-making within the WHO structure. I would argue that the collaborative and democratic nature of these consensus statements strengthens the obligation of member states to abide by them.

These consensus statements include the following:

- * There is no public health rationale to justify isolation, quarantine, or any discriminatory measures based solely on the fact that a person is suspected or known to be HIV-infected.
- * Serosurveys must involve informed consent, confidentiality and counselling, or be anonymous.
- * Voluntary testing must involve informed consent, confidentiality and counselling.
- * Screening travellers or demanding proof of seronegativity will not prevent the spread of

AIDS.¹¹⁴

As may be seen from these and other consensus statements, the WHO has taken a very strong position against all of the kinds of liberty-restricting legislation which were discussed above. These positions are backed by numerous kinds of technical and non-technical arguments.

As an example, let us return to the question of entry restrictions. Aside from the problems of encouraging xenophobia, GPA documents argue that such measures would divert resources away from much-needed educational or other prevention programs and would provide a false sense of security since there are innumerable loopholes in such plans. Some of the loopholes are the "window" period during which an HIV-infected person will test negative, the fact that certain groups would be exempted from the tests (e.g. tourists in Cuba and other countries), and the pragmatic difficulties of carrying HIV-negative "certificates." How long should such certificates be good for? Cuba actually avoids the latter problem by simply testing all foreign residents itself, but the other concerns are certainly valid for Cuba as well as for other countries.

Thus, it is clear that the WHO guidelines are based on valid arguments and sound reasoning as well as a broad international consensus. In the example of entry restrictions in pattern III countries, it is evident that the unique epidemiological situations of these countries do

not justify the violation of WHO guidelines regarding international travel.

In a similar way it may easily be argued that all of the restrictive legislative measures described above are problematic, and the fact that such measures violate WHO consensus statements on AIDS is one important reason to be concerned about them. However, it is valid and important to recognize that violations of these guidelines are very common, and, as we have seen, they are not in any way restricted to a particular geographical or political type of country. Cuba is not alone in having restrictive legislation regarding AIDS.

Another important point is that not all WHO consensus statements will necessarily fit equally well in all countries. For example, another WHO consensus statement is the following:

* HIV-infected mothers should not be discouraged from breastfeeding. Infection through nursing represents only a small, incremental risk to the infant and is far outweighed by the benefits of breastmilk.¹¹⁵

This advice is clearly most appropriate in poor countries, and might be worth questioning in developed nations in which high-quality formula and clean water are readily available. One could have a lengthy debate about this particular issue; the point is that although WHO guidelines are carefully prepared and democratically agreed upon, they still must be

applied and interpreted in specific contexts.

Summary

Overviews of the world as a whole must necessarily be painted with broad brush strokes. The division of the world into three or four epidemiological patterns is valuable, and highlights important similarities, but also tends to mask key differences. Therefore, simple epidemiological comparisons between a nation and its region are not easily performed. This is particularly true of Cuba, which is unusual for a number of reasons. For example, Cuba is a poor country, but unlike most poor countries, it has a highly developed health infrastructure.

The consensus of the international community regarding AIDS prevention is also painted in broad brush strokes. As discussed above, the consensus is to reject all forms of repressive legislation in the fight against AIDS. These recommendations are widely assumed to be morally correct and applicable to all the nations of the world, and there are several strong arguments to support such a position.

Yet the broad brush strokes of the WHO are not sufficient to fully analyze a nation's response to AIDS. As we have seen, many nations, in spite of their nominal support for the WHO recommendations, continue to violate the letter and spirit of the consensus statements (Cuba is the most extreme example, but it is far from being the only

one). Also, the guidelines might at times be too general to apply to every specific circumstance (e.g. the pro-breast feeding recommendation). One might conclude that there are a variety of obstacles which prevent nations from sticking to the WHO guidelines. Thus, a meticulous analysis of the particular issue and its local application is necessary to understand (and thereby criticize in a constructive and effective manner) any country's efforts to stop the spread of HIV and AIDS.

In chapters VII and VIII I will provide a careful assessment of the the two key issues, testing and quarantine, by applying and interpreting international standards within the specific Cuban context.

VI. A QUESTION OF EFFECTIVENESS

Cuban government officials have put forward a variety of arguments to try to prove that their policies have worked. At various times they have stated that the empirical evidence proves their success in slowing the progression of disease in infected individuals and in stopping the spread of the virus. If these claims have any truth to them, they certainly constitute a strong argument - if not a sufficient justification - in favor of the Cuban approach. This chapter is therefore devoted to an evaluation of these claims and of the commentaries of international observers with respect to the effectiveness of the Cuban program.

The high ratio of well to sick

One early argument put forward by Cuban health officials was that the high ratio of asymptomatic seropositives to people in various stages of clinical disease proved that the sanatorium was effective in keeping people well. For example, the first public MINSAP report on AIDS policies in April 1987 stated,

not one of these carriers has developed AIDS nor presented any symptoms of this disease, which demonstrates the highly positive results of the preventive measures adopted to impede the development of the disease among carriers, thus protecting in an effective way the health and life of these citizens.¹¹⁶

Fidel Castro made the same argument in a press conference the following September:

An average of 30 out of every 100 carriers in any country get the disease in a relatively short time, while in Cuba, out of every 100, very few have become ill, which has proven that the lives of many carriers can be saved.¹¹⁷

Unfortunately these arguments don't hold up. For one thing, the time period under question is short. Los Cocos opened in April 1986 with 24 residents; a year later there were 108. Thus most of the cohort referred to in the MINSAP article had been under study for less than a year. Since the median time from infection to development of AIDS is estimated at 10 years,¹¹⁸ it is not at all surprising that few were sick in mid-1987. In studies performed at the Walter Reed military hospital in Washington, it was found that a majority of HIV patients studied for one year were still in the same stages at the end of the year.¹¹⁹

Furthermore, as MINSAP figures demonstrate, many of Los Cocos' residents progressed to more advanced stages of disease over the two years following these statements. Thus by May of 1988, only 65.2% of Los Cocos residents were classified as asymptomatic; a year later (having lost 8 of the sickest and having gained 54 new residents who were on average probably less sick), that figure had dropped to 58%.¹²⁰ In general terms, these figures are not inconsistent with the U.S. studies of disease progression rates. So in

all the Cuban experience in treating HIV infection does not appear to have produced clinical results that are dramatically different from those of other nations. However, mean survival times of Cubans with HIV disease have not yet been systematically studied.¹²¹ It would be interesting if someone would do such a study.

The low ratio of well to sick

As we have seen, Cuban officials initially claimed that the high ratio of well to sick seropositives proved that the sanatorium worked to prevent progression of the disease. It is highly ironic, therefore, to note that only one year later, health officials were making almost the exact opposite argument, i.e. that the low ratio of well to sick seropositives was evidence that the sanatorium was effective in stopping the spread of the virus:

All of these reasons lead us to believe that the prevalence of HIV among the Cuban population is really very low and that it is mainly due to the nationwide program which allows for relatively early detection and to isolation of those detected to keep it from spreading in geometric proportions. Further evidence of this reasoning is that in Cuba the proportion of carriers to patients is 5.4 to one, as compared to an estimated 60-100 to one in countries where no checks exist. Thus, if we use as a starting point the number of carriers per patient reported by countries with no AIDS control, we would deduce that in Cuba, where there are 34 known cases, there should be about 2040 - 3400 carriers, whereas only 230 seropositive cases (including the 34 patients) have been detected in close to 2,260,000 HIV tests.¹²²

It would appear that advocates of the Cuban plan are trying very hard to have their cake and eat it too. The ratio has to be either high or low. If it is high, as more recent arguments will have it, does this imply that care at the sanatorium is ineffective in impeding progression to full-blown AIDS?

But let's leave aside for a moment the question of the effectiveness of care and consider the central argument presented, that the low ratio implies success in prevention of transmission. It would be helpful to have a thorough data base to actually look at this ratio, but unfortunately such data are difficult to obtain, in part because of the uncertainties of classifying a patient as a "case" of AIDS. Cuba uses the CDC surveillance case definition guidelines, in which all patients who have symptoms more serious than persistent generalized lymphadenopathy are classified into category IV.¹²³ This group, therefore, includes many who do not fit the usual criteria for an AIDS diagnosis. (And when the numbers are small, uncertainties of staging can easily skew the ratios.) However, the following table presents the best available information:

Table IV: Total seropositives per AIDS case, 1987-1989¹²⁴

<u>Date</u>	<u>Total seropositive</u>	<u>Total # of cases*</u>	<u>Ratio**</u>
Mar. 87	108	3	36.0:1
Sep. 87	147	6	24.5:1
Jan. 88	174	27	6.4:1
May 88	227	33	6.9:1
Feb. 89	275	51	5.4:1
Nov. 89	356	63	5.7:1

*Includes those who have died of AIDS-related causes. Cases are those defined as CDC category IV, or those described as clinically ill.

**Rounded to the nearest tenth

These data do indicate a decline in the number of asymptomatic seropositives per clinical case. Assuming that few seropositives have escaped the "net" of widespread testing, it is reasonable to conclude that at this point Cuba does indeed have a fairly low ratio of seropositives to clinical cases.

How does this compare with other countries? Of course good seroprevalence data are frequently lacking in the evaluation of the level of infection in many countries. Even in the United States, seroprevalence estimates have been subject to major disagreements and revisions. And in many poor countries, few seroprevalence studies have been

conducted and the estimates are extremely rough.

Nonetheless, there is reason to believe that as the Cubans claim, ratios of infected people to AIDS cases tend to run higher than what we have seen in the Cuban case.

For example, in 1988 the Brazilian National Ministry of Health estimated that the total number of Brazilian seropositives was approximately 50 to 100 times the present counted caseload, adjusted for under-reporting.¹²⁵

Similarly, international estimates by the WHO/GPA range from a ratio of about 12:1 for pattern I countries, to 100:1 for pattern III countries. Latin America and the Caribbean, (which as we have seen are currently classified as pattern I/II) has an overall ratio of about 40:1.¹²⁶ If this region is taken as the most appropriate comparison for Cuba, it could indeed be argued that Cuba appears to have a lower seroprevalence based on its caseload than is the general regional trend.

But there are undoubtedly substantial variations from country to country, based on factors such as the "age" of the epidemic (early in the epidemic curve the ratio will of course be much higher, since most infections are "silent" and have not showed up as cases) and the particular risk characteristics of the population. Also, estimates of total HIV-infected individuals are beginning to be revised downwards, as accumulating data indicate that the early estimates were too high. In the United States, for example,

the current estimates of HIV seroprevalence are in the neighborhood of 1 million, and the caseload as of April 1, 1990 was 128,319; thus the seropositive:case ratio in this country is actually only around 8. Clearly, it is inappropriate for Cuba to blithely assert (as they have done¹²⁷) that without their control measures the seropositive population would be 50 to 100 times their present case load.

There are several ways that these data could be interpreted. On the one hand, the Cuban ratios are only slightly lower than those of some other countries, such as the United States; this by itself does not seem to amount to substantial proof that the Cuban plan is highly successful in controlling AIDS. However, it does seem notable that although AIDS came fairly late to Cuba (first case reported in 1986) the Cuban ratio most closely resembles the ratios of those regions in which the epidemic started early. In other words, the rapidly declining seropositive:case ratio in Cuba could be taken as evidence that the Cubans have sharply truncated their epidemic curve. But more evidence is needed.

Doubling times

The preceding epidemiological evaluation is not without uncertainties. Happily, there are other methods which may be used to evaluate the success of the Cuban plan. One common measure of the rate of spread of an epidemic is to

examine the doubling time of the caseload. Cuban officials have argued that their doubling times are much longer than those of other nations:

The statistics are always going to increase. [However] it's not a geometric growth, but rather a slow one, and this makes it possible for us to gain time and to see what will happen in the world [in terms of vaccine or treatment]... In all countries, clinical cases of AIDS double every six months and the number of seropositives is unknown. In Cuba, the situation is quite distinct; in proportion as the testing increases, the rate of positivity goes down.¹²⁸

To fairly evaluate the claim that the Cuban doubling time is longer than the rest of the world's, the following doubling times for the first three years of AIDS in Cuba have been calculated:

Table V: Doubling times¹²⁹

<u>Time interval</u>	<u>Increase in cases</u>	<u>Doubling time</u>
March-Sept. 1987	3 to 6	6 mos.
Sept.-Dec. 1987	6 to 24	1.5 mos. (avg.)
Dec. '87-Dec. '88	24 to 51	12 mos.
Dec. '88-Nov. '89	51 to 63	33 mos.

It should be noted that the uncertainties surrounding case definitions and precise dating of case reports make these data somewhat approximate. Nonetheless it does appear that after an initial period of very rapid doubling, the doubling

time in Cuba has lengthened considerably and is currently much longer than the six-month figure cited above by Dr. Terry. Does this indicate the success of the Cuban model?

Unfortunately, growth rates of epidemics are a complex matter, and there is no standard curve with which to judge the performance of all nations.¹³⁰ However, it is certainly not true, as Dr. Terry asserted, that all countries have shown growth rates which result in six-month doubling times.

Nevertheless, the general trend towards frighteningly short doubling times is certainly evident. For example in Mexico the average doubling time during the first 7 years of the AIDS epidemic was 7.7 months. Initially, cases in Mexico followed a pattern of exponential increase; growth has recently slowed. The deceleration, however, appears to be much less pronounced than in Cuba. Mexico's projected doubling time in 1994 will be approximately 13.8 months.¹³¹

Numerous other countries have reported doubling times of a year or less. Examples include Colombia,¹³² Brazil,¹³³ and the English-speaking Caribbean as a whole.¹³⁴ However, it must be stressed that the expected rate of increase in numbers of cases of AIDS is a very difficult figure to calculate, depending as it does on a plethora of local conditions. It is difficult, therefore, to know what the rate of increase in cases - or the doubling time of the case load - would have been if stringent measures had not been instituted in Cuba.

Thus in evaluating the Cuban doubling times it must be recognized that there is no way to know with certainty what would have happened had they taken a different approach. Also, the data on Cuban doubling times are somewhat incomplete; as more data accumulates, the picture may become more compelling. However, if the trend continues - if the Cuban doubling time remains high or even lengthens - then these data should be interpreted as strong evidence that the Cubans are slowing substantially the spread of AIDS in their country.

Prevalence rates

One of the epidemiologically unusual facts about Cuba is that due to the widespread testing, abundant data are available on seroprevalence of HIV. In fact there are probably much more accurate estimates of seroprevalence in Cuba than in any other country in the Western hemisphere. Therefore, arguments about effectiveness based on seroprevalence data should be more easily evaluated than the previous arguments, which were based on skimpy data about very small numbers of cases.

Therefore let us turn to the question of seroprevalence rates. Advocates of the Cuban plan have made various kinds of claims to the effect that seroprevalence studies illustrate the success of the program. The simplest of these arguments looks at the overall seroprevalence from all

epidemiological studies conducted on a year-by-year basis. For example, Santana states that the following figures illustrate a slowing of the rate of HIV transmission in Cuba:

Table VI: Seroprevalence among all those tested by year¹³⁵

<u>Year</u>	<u>Number tested</u>	<u># positive</u>	<u>Rate (%)</u>
1986	603,761	99	.0164
1987	880,608	75	.0085
1988	<u>1,447,880</u>	<u>85</u>	<u>.0059</u>
Total	2,932,249	259	.0088

These data are certainly impressive at face value: each year, the percentage of those tested who turn up positive decreases. But in order to compare one year's cohort to the next, the types of people being tested need to be similar. In other words, if the Cubans tested mostly high-risk persons in 1986 and mostly low-risk persons in 1988, the comparison would prove very little about the overall success in controlling transmission.

And in fact it appears that something close to this scenario may well have occurred. According to Dr. Galbán García of MINSAP, the first groups to be tested under the new program in 1986 were those most suspected of being at high risk. Although screening of blood donations was instituted early, tests on hospital inpatients and pregnant

women (two low-risk groups) were not begun until mid-1987 and were sharply increased in 1988. Similarly, studies of the general population in selected geographical areas did not begin until 1987 and were expanded in 1988.¹³⁶ So the overall pattern of declining seroprevalence may be more an artifact than a true representation of declining prevalence.

Seroprevalence figures based on consistently defined groups of people, however, have also been used to demonstrate a declining rate of transmission. At first glance this would seem to be somewhat better evidence in favor of the success of the policy. The best example is that of blood donors, which show the following pattern:

Table VII: Seroprevalence among blood donors by year¹³⁷

<u>Year</u>	<u>No. tested</u>	<u>No. +</u>	<u>Rate (%)</u>
1986	304,856	14	.0046
1987	491,884	6	.0012
1988	584,954	2	.0003

In a prominent article in Granma, the Cuban government argued that data such as these prove the success of their control strategy.¹³⁸ However, there is a major flaw in the argument that these data constitute strong evidence of diminished transmission. To state the obvious, there is a rather large disincentive to be a blood donor in Cuba if you have any reason to suspect that you might be infected with

HIV; the disincentive would presumably increase as news of the initially secret sanatorium at Los Cocos got around. So the blood-donor seroprevalence argument is also suspect.

Similar arguments have been made on the basis of the test results of other groups. For example, in their contribution to PAHO's collective study of AIDS in the Americas, Terry et al. argue that:

A prospective analysis of the prevalence of seropositivity among pregnant women reveals a declining trend similar to that observed among blood donors. In 1987 (when this investigation began) three seropositive pregnant women were detected from among the 79,063 tested, yielding a seroprevalence of 0.0038 per 100 tested, while in 1988 only one seropositive pregnant woman was found among the 83,949 tested, yielding a prevalence of 0.0012 per 100 tested.¹³⁹

It is certainly better to compare seroprevalence data on pregnant women in different years than seroprevalence data on blood donors, since it is less likely in Cuba that pregnant women will evade testing (although presumably women who fear they may be infected might simply avoid pregnancy altogether). However, the dramatic decline in seroprevalence which Terry et al. refer to is actually based on very few data points. The 1988 numbers used in the article are mid-1988 figures; by the end of that year 203,218 pregnant women had been tested and 6 seropositive cases had been found.¹⁴⁰ This yields a rate of .0030% for 1988 - considerably higher than the .0012% figure quoted by

Terry et al., although still slightly lower than the .0038% rate calculated for 1987. In other words, seroprevalence might be declining slightly for this group, but the case is not nearly as clear-cut as has been claimed. So the argument that seroprevalence trends among pregnant women prove the effectiveness of the policy is on much shakier ground than it might appear at first.

Even more troubling is the following: it appears that Terry et al. may have selectively reported only those data which tend to show a decrease in seroprevalence over time. When seroprevalence rates are calculated on some of the raw data for other well-defined groups tested, the numbers do not support the story of declining seroprevalence:

Table VIII: Seroprevalence rates among hospital inpatients¹⁴¹

<u>Year</u>	<u>No. tested</u>	<u>No. +</u>	<u>Rate (%)</u>
1987	99,348	2	.0020
1988	554,522	12	.0022

Table IX: Seroprevalence rates among patients at STD
clinics¹⁴²

<u>Year</u>	<u>No. tested</u>	<u>No. +</u>	<u>Rate (%)</u>
1987	9,552	0	0
1988	95,986	9	.0094

Table X: Seroprevalence rates among international
travelers¹⁴³

<u>Year</u>	<u>No. tested</u>	<u>No. +</u>	<u>Rate (%)</u>
1986	241,983	54	.0223
1987	93,926	19	.0202
1988	89,019	22	.0247

Of course the data on infection rates among international travelers say little about the control of transmission within Cuba. However, what is clear is that Terry's group chose to highlight the data which would support their case, and not to report calculated rates for other population groups. Some groups, such as hospital inpatients and patients at STD clinics, appear to show a slight trend towards increasing seroprevalence over time.

It must be recognized, however, that the changes in rates are slight and the time intervals are short. A much

more thorough evaluation of seroprevalence rates will only be possible as more data become available. At this point the best that can be said is that the changing rates of seroprevalence over time do not prove that the Cuban plan has successfully slowed transmission of HIV in Cuba.

Absolute numbers of cases

One very easy argument which is often used to demonstrate the effectiveness of the Cuban plan is to simply point to the low overall numbers of infected people and of cases of AIDS. For example, one Cuban doctor commented,

The number of cases is very small... The cases of AIDS that have appeared are all controlled, so there is very little circulation of the virus among the population... [thus] the index of positivity is possibly the lowest in the world; practically insignificant, in comparison, for example, with the development of this disease in other countries.¹⁴⁴

Assuming that the statistics provided by MINSAP are correct, it is certainly valid to point out that the prevalence of HIV and the incidence of AIDS are low in Cuba. And this is undeniably a good thing.

However, countries of the world vary widely in case rates. Even within WHO/GPA "regions" like Latin America and the Caribbean (co-equivalent with epidemiological pattern I/II), there is a wide variation. For example as of June 1988 the case rates in this region (for countries reporting

more than 10 cases) ranged from 3 per million in Peru to 1378 per million in French Guiana.¹⁴⁵ It is true that Cuba fits near the bottom of this scale (like Peru, Cuba had 3 cases per million as of June 1988), but this does not constitute conclusive proof that Cuba is doing a much better job of preventing AIDS than everyone else.

Furthermore, some international epidemiologists have stated that there is limited value in comparisons of case rates:

It is ...difficult to make any significant comparisons when discussing absolute numbers of AIDS cases reported from an individual country or subregion because of differences in the population base, and because of variable inaccuracies in case reporting rates. Furthermore, a comparison of the absolute number of cases fails to describe the actual economic and health impact of AIDS within some countries, since many countries are in different stages of development...¹⁴⁶

One could argue that some of these concerns make the Cuban example seem even more favorable, since under-reporting is probably a much greater problem in countries with less well-developed health infrastructures. Also, Cuba might be said to have a fairly high at-risk population base, given the extent of Cuban "internationalism" and the high level of sexual activity on the island; this again makes the low Cuban case rate appear more impressive. However, it is still true that there are other countries in Latin America and the Caribbean with similar or lower rates.¹⁴⁷

Accuracy of the numbers

But there is a more significant challenge to the idea that Cuba's low absolute numbers prove the success of their policy. This challenge comes from some traditional opponents of the Cuban revolution, who argue that the statistics provided by MINSAP are simply not reliable, and that there is reason to believe that seroprevalence in Cuba is much higher than what is reported. This position is based on two arguments. The first argument is that the Cuban military presence in Angola must have resulted in a high level of infection among Cuban soldiers, who then brought the virus back to Cuba. The second argument is that HIV antibody testing of blood samples drawn from 1980 Cuban immigrants to the U.S. ("Marielitos") indicates a much higher level of infection in Cuba than would be consistent with MINSAP figures.

As mentioned in chapter III, the first of these arguments is partly informed by the political motive of criticizing Cuban foreign policy in Africa. The argument forms an interesting twist on the fundamentalist Christian claim that AIDS is God's punishment to gay people for their sexual orientation. In this case AIDS is depicted as just retribution to Cuba for its foreign policies which support other Marxist governments.¹⁴⁸ In this sense the argument is really more an attack on Cuba's foreign policy than an

attack on Cuba's AIDS policy.

However, even some liberal critics of Cuban AIDS policy such as Ron Bayer have agreed that on the face of it, you would think that there would have been more infection among soldiers stationed in Angola:

Angola borders on Zaire. Zaire reports itself within the context of Africa to be a fairly high-prevalence nation. Angola reports to the WHO that it has virtually no cases. It's hard for me to believe that the border between Zaire and Angola is completely un-porous...It's hard to believe that a neighboring country would have such disparate levels of infection... Given what we know about the history of armies, it's hard to believe that Cuban soldiers have not bought the services of prostitutes. And it's hard to believe that some of these prostitutes did not cross the border from Zaire, and that some of the prostitutes weren't infected.¹⁴⁹

Such scenarios are a matter of speculation. As Bayer later noted, many factors may have influenced this possible scenario - the soldiers may have had insufficient money or free time to spend on prostitutes, for example. Elsewhere, Bayer has argued that the numbers provided by MINSAP are probably accurate, and that "the low rate among Cuban nationals returning from abroad is consistent with the relatively low rates reported from Angola."¹⁵⁰ To the charge that soldiers were massively infected in Africa, the Cuban government has replied that their empirical data show that this simply isn't true. They do attribute a sizeable

portion of their infections to African exposure (approximately a third of the total)¹⁵¹, but they deny that a larger cohort of people was infected in this way. Few explanations are offered as to why the soldiers may have escaped infection. Further information on the risk behaviors of Cubans in Angola would help to shed light on this issue.

The second argument questioning the accuracy of MINSAP figures is based on a specific laboratory study, and as such is somewhat less speculative than the first argument. This 1987 study consisted of a series of HIV antibody tests performed by researchers at the University of Miami on stored blood samples which had been drawn from Mariel refugees in 1980. (The blood was originally drawn in order to study hepatitis antigens.) Of the 990 samples studied, 20 (2.02%) were repeatedly positive by ELISA. With confirmatory Western blot assays, only 4 (.4% of the total sample) were considered unequivocally positive, which was defined as positive for both p24 and p41 antigens. Two more were p24+ but only weakly p41+, and 14 were deemed equivocal, since they were p24+ only.¹⁵²

These data have been used by various critics of Cuba to argue that the level of infection in Cuba is actually quite high.¹⁵³ However, the data are often mis-construed in these arguments. Thus for example in 1987, one of the authors of the Miami study wrote in a letter to JAMA that "Out of 990

randomly selected blood samples collected in 1980, twenty were positive for HIV infection (2.02%)."¹⁵⁴ But as Bayer points out,

Gordon's conclusion concerning his own study, that 2.02 percent (20 samples) were positive, is incorrect given our understanding of the technology of testing. The original report cites only 4 (0.4 percent) of the samples as 'unequivocally positive.' According to current internationally accepted standards, only the samples clearly reactive to two bands would be considered positive.¹⁵⁵

Bayer further argues that the Marielitos were not a representative sample of the Cuban population, since they included a disproportionate number of prisoners, mental patients, and homosexuals. Thus the prevalence of HIV infection among the Marielitos might very well have been higher than that of the rest of the population. Studies done by MINSAP do reportedly show that prisoners have higher rates of HIV infection than other groups tested, although the differences are not large.¹⁵⁶ Given these considerations, it would be fair to say that the Miami study does not offer conclusive proof that HIV infection in Cuba is drastically higher than what has been reported by MINSAP.

[It would be interesting to further explore the question of the equivocal samples. In February of 1989 it was reported that the 268 seropositives then at Los Cocos included one who was infected with HIV-2.¹⁵⁷ Given that the core proteins of HIV-1 and HIV-2 (such as p24) are fairly

similar, whereas the envelope proteins (such as gp-41 on HIV-1) differ substantially, it is interesting to speculate that some of the Marielitos might have been infected with HIV-2. HIV-2 antibody-positive sera have been shown to recognize the core proteins of HIV-1, but not the envelope glycoproteins.¹⁵⁸ However, some workers have reported that equivocal Western blot assays (with only one band positive) may occur in completely uninfected samples.^{159]}

But let us leave aside for a moment the uncertainties of the Miami blood study. There is one additional reply to the charge that HIV infection in Cuba is widespread. That argument was eloquently stated by Bayer and Healton:

one must ask why the Cuban authorities would have undertaken a quarantine of those they claim are infected while permitting a much larger number to remain free, when their approach to AIDS has evoked widespread international criticism. Certainly such a venture, without any plausible possibility of limiting the spread of HIV infection, would have represented the height of political folly.¹⁶⁰

This is probably the most compelling single argument in favor of the reliability of MINSAP statistics.

It is the conclusion of this author that MINSAP statistics may be assumed to be reliable, within normal bureaucratic limits. The low prevalence and incidence rates reported by MINSAP may therefore be considered partial evidence in support of the contention that the Cuban AIDS plan is working.

Has it worked? Will it work?

In examining the opinions of various commentators and journalists in the United States, it is somewhat amusing to note that comments about the effectiveness of the Cuban plan tend to fall into one of two camps. Some say the entire plan is destined to backfire with the inevitable result of more cases of AIDS. Others state that it probably will work to reduce the spread of the disease. (These writers often question the costs that will be paid to achieve that goal.)

An example of the first group is a letter to Fidel Castro by H. Daniel, a Brazilian PWA, who states,

Cuba could take pride in its health care system. Could, if it weren't for the way it treats those who are HIV seropositive, whether sick or not, burying them in an isolation which has no technical justification, which goes against all scientific advice and which seriously impinges on human rights...There is no possible justification to defend [Cuba's actions], except for those based on the most reactionary forms of prejudice against gays. Certainly Cuba will soon discover that these measures are counterproductive: people with AIDS will be placed in the position of enemies, even more difficult to locate, and the epidemic will not be overcome.¹⁶¹

Daniel is eloquent in his sincere defense of individual liberties and his plea for humane treatment of PWAs. But his knee-jerk assumptions about the technical value of the Cuban approach are worth picking apart. There are actually two ideas behind the oft-repeated mantra that mandatory

testing and quarantine are scientifically ill-advised. The first (which Daniel alludes to) is that such measures will cause people to evade testing. The second is that it is pointless to quarantine since casual contact does not spread the virus. Thus in reply to Daniel, one might ask: don't the Cubans in fact have just the sort of mixture of popular confidence in the health authorities and widespread social control, which might make mandatory testing work? And in saying there is no technical reason to isolate, aren't you assuming that the quarantine is designed to prevent spread by casual contact? For in fact it is not. It is designed to control sexual contact between HIV+ and HIV-. That is the fundamental reason for the policy.

These thoughts are offered not as an ethical defense of Cuba's position, but rather as a note of caution. Those who wish to criticize Cuba on technical grounds should examine their assumptions and consider the peculiarities of the Cuban case; for as this chapter has illustrated, there are several legitimate reasons - though not as many as are claimed by the Cuban government - to tentatively conclude that the Cuban approach may be helping to slow the spread of HIV infection.

Of course, there are several logically or technically legitimate reasons to question whether the Cuban plan may be effective. To the above questions, Daniel might reply that in spite of the high degree of social control, people who

fear they may be infected will find ways to avoid being tested.¹⁶² And he might add that it is impossible to control completely the sexual behavior of the isolated seropositives, given that they are allowed regular excursions and home visits. Another consideration is that the ongoing testing program will have to be quite thorough to catch in a timely manner all new cases of infection brought in from outside or missed during previous sweeps. (And tourism in Cuba is growing.) However, to some extent these issues would be addressed if the AIDS education program were sufficiently expanded and improved.

The second group of commentators recognizes the possibility that the Cuban approach may succeed. For some, such as Nicholas Wade of the New York Times editorial board, proof of success would be sufficient to justify the policy:

Cuba is in effect conducting an experiment. If, in a decade, its population has gained a unique protection from the scourge of AIDS, it can contend its unique quarantine program was justified. If not, hundreds will have been deprived of liberty for nothing.¹⁶³

Others disagree; Ron Bayer, for example, believes there is "no doubt that Cuban policy will dramatically limit the toll of HIV infection in Cuba," but in spite of this inevitable success, he considers the policy morally unjustifiable.¹⁶⁴

In this chapter I have shown that the evidence for the success of the Cuban plan is weaker than Cuban officials

claim that it is. Some evidence (well:sick ratios; long doubling times; low absolute numbers) does tend to support the claim of success. Yet other data, such as the changes in seroprevalence over time, have been inappropriately presented - one might even say manipulated - to create false proof of success.

In the next two chapters, I will consider whether the policies may be justified on moral and ethical grounds, and whether proof of success should influence that judgement.

VII. TESTING AND SCREENING: PRAGMATIC AND ETHICAL ISSUES

This chapter will provide a close look at HIV testing and screening. After considering some definitions and examining the various ways that the test may be used, we will proceed to a detailed discussion of the basic ethical principles and more specific ethical guidelines of testing and screening programs. Several formulations of such guidelines will be reviewed, and the Cuban program of HIV antibody testing will then be evaluated with respect to these guidelines.

The goal of this chapter is to answer the following questions: how exactly is the test applied in Cuba? What are the pragmatic problems of such a program? And how does the Cuban program of testing fit with or violate accepted ethical standards on HIV testing?

Definitions

One point of frequent confusion is the difference between testing and screening. The distinction is the following: HIV testing is "a serological procedure for identifying HIV antibodies or antigens in an individual, whether recommended by a health care provider or requested by the individual."¹⁶⁵ HIV screening, by contrast, refers to "the systematic application of HIV antibody testing, whether voluntary or mandatory, to any or all of the following: entire population; selected target populations; donors of

blood or blood products and cells, tissues, and organs."¹⁶⁶

Testing and screening may both be implemented in a variety of ways. One key variable is the degree of free choice which the person being tested may exercise. A researcher with the WHO's Global Program on AIDS describes three possible scenarios: voluntary testing, mandatory testing, and compulsory screening.¹⁶⁷ The difference between mandatory and compulsory is that in the mandatory setting, the test is required for a benefit or service that the individual has voluntarily requested, and the person can theoretically refuse to be tested by refusing the benefit or service; in compulsory screening the test is required by law regardless of the individual's desires.

Most commentators on the issue gloss over this distinction and use the term "mandatory" to refer to all applications of the test which are mandatory or compulsory. In practice, there is a blurry line between the two situations. Mandatory testing/screening may feel compulsory if the situation in which the test is required is difficult to avoid, or central to one's life plans - an example would be mandatory screening of applicants for marriage licenses. But if it is easy to choose not to be a member of the group being tested, then the experience becomes much less coercive. Such is the case with mandatory screening of blood or tissue donors. The important point, then, is that mandatory testing/screening encompasses a range of possible

situations of increasing coerciveness, with compulsory screening at the far end of the spectrum.

Another key term in this discussion is the concept of routine testing. This term may be used in different ways, but is commonly thought of as "the testing of certain individuals or groups recommended by health care providers and consented to by the person to be tested after counseling."¹⁶⁸ In other words, the health care provider suggests and encourages the test, although the person has the right to refuse it.

Another commentator sees only two categories of applications of the test: voluntary and mandatory. In this analysis, "a truly voluntary use of the test requires that the person is given full information and specifically asked to consent before undergoing the test."¹⁶⁹ Routine testing in this view is simply "a confusing hybrid between **voluntary** and **mandatory**,"¹⁷⁰ which only serves to dilute the strength of the informed-consent requirement in voluntary testing.

The main point is that there is a spectrum of possible applications of the test. In the United States, voluntary, routine, mandatory and compulsory testing and screening programs have all been proposed and hotly debated. By and large, a "broad voluntarist consensus" has emerged from these debates, so that voluntary (usually confidential or anonymous) testing is the norm in this country.¹⁷¹ However, advances in treatment have led to calls for increased

routine testing.¹⁷² Also, there are several mandatory testing programs already in place in the U.S. (military recruits and applicants for Foreign Service jobs, for example), and more such programs continue to be proposed.¹⁷³ So the debate about the proper use of testing technology is by no means over, in the U.S. or the rest of the world.

Cuban applications of the test

The Cuban program of testing for HIV infection is commonly described as "compulsory screening of the entire population,"¹⁷⁴ but the true situation is slightly more complicated. Certainly the goal is to test the entire population (or at least the entire adult population). The methods used to accomplish this goal, however, encompass a variety of mandatory and mandatory/routine screening programs. For example, there is mandatory screening of all those returning from abroad and all foreign students studying in Cuba. Such programs are probably quite strictly enforced.

Other screening programs may be somewhat less rigid. Hospital in-patients are routinely screened without informed consent, although according to anecdotal accounts, requests to forego testing in this setting are accepted without incident.¹⁷⁵ Similarly, many adults have been screened with no formal mechanism of informed consent during geographical seroprevalence studies, but "dozens of persons" have

reportedly chosen to refuse the test, and have suffered no reprisals.¹⁷⁶

It is striking to the foreign visitor that in Cuba there is very little use of the concept of informed consent, either within or outside the sphere of HIV and AIDS. When asked about informed consent (for example, for clinical procedures or experimental drug trials), Cuban doctors commonly respond that since they would never do anything to hurt their patients, and since there is no profit motive in Cuba, such concerns never arise. People just trust their doctors, they say.

The fact that there is no formal mechanism of informed consent in Cuba does not necessarily mean that the dictatorial will of the health care provider is routinely imposed on Cuban patients with no opportunity for discussion. Such discussions are simply more informal in Cuba than in the United States. As discussed in chapter II, the Cuban health care system tends to be highly respected by the population; the medical hierarchy and authority of physicians are seldom questioned. In this climate there are simply fewer occasions, in general, in which patients might choose to question their doctor's directives. In daily clinical practice, an informal assumption prevails that doctor and patient will share the same goals.

In general this might work fine. But what about the case of HIV antibody testing? Here it would appear that the

goals of doctors, as representatives of the state (supposedly acting to protect the public health), are potentially in direct conflict with the goals of the patient, who might well wish to avoid being tested.

In summary, Cuba tests for HIV infection mainly via ongoing mandatory screening programs, which happen both in clinical and non-clinical settings. Some of these programs are probably quite firmly mandatory. In other programs there are loose and informal mechanisms for refusing to take the test; these latter programs might be considered more routine than strictly mandatory. In any of the testing programs, there is only the slimmest of assurances of confidentiality (there have been some efforts to keep the information from neighbors, co-workers, etc.) However, the government obviously knows the results of the tests, and acts on that knowledge.

As discussed in chapter IV, there is some evidence that Cuba's mandatory or semi-mandatory screening programs are surprisingly well received. However, there are no hard public-opinion survey data to quantify this finding, and in any event generalized public acceptance of mandatory screening programs does not constitute a sufficient justification for such programs. What would constitute sufficient justification for such programs? The next section will attempt to answer this question by taking a closer look at the ethical basis of HIV testing.

Principles of medical ethics

A thorough analysis of the ethics of any health policy might well begin with a restatement of some commonly accepted ethical principles of medical practice. These have been expressed in various ways. Bayer, Levine and Wolf describe four key principles: the principle of respect for persons and the principles of harm, beneficence, and justice:

1. **Respect for persons** requires that individuals be treated as autonomous agents who have the right to decide their own destinies. It requires that persons be given the opportunity to decide what will or will not happen to them...
2. **The harm principle** permits limitations to be placed on an individual's liberty to pursue personal goals and choices when others would be harmed by those activities.
3. **Beneficence** requires that we act on behalf of the interests and welfare of others...
4. **Justice** requires that the benefits and burdens of particular actions be distributed fairly...¹⁷⁷

Others have slightly different formulations. For example, Lo, Steinbrook et al. describe five ethical principles that guide all clinical practice: "autonomy, confidentiality, beneficence, nonmaleficence, and justice."¹⁷⁸ In this paper the four principles quoted above will be used for the sake of simplicity.

Testing guidelines

Several authors have attempted to establish basic ethical guidelines for evaluating and implementing HIV testing programs. Some spring directly from a consideration of basic principles of medical ethics, like those described above. Other guidelines are straightforwardly pragmatic.

One early (1986) formulation of guidelines was provided by Gostin, Curran and Clark, who held that any mandatory HIV testing program should meet the following criteria: (1) The population should have a high reservoir of infection (to hold down costs, intrusiveness, and false positive results); (2) There should be a high risk of transmission among the group being tested; (3) The test results should be used effectively; (4) The critical consequences of screening should not outweigh the benefits and (5) There should be no less restrictive measure or intrusive means available to accomplish the same goals. These guidelines were published during a time that numerous mandatory testing proposals were on the table in the United States.

The following year (1987) Bayer, Levine and Wolf published a more general set of ethical guidelines for any HIV testing program (not just mandatory programs).

According to these guidelines, any testing or screening program must adhere to seven prerequisites, which are based on the four ethical principles described above. The seven prerequisites are as follows:

1. The purpose of the screening must be ethically acceptable.
2. The means to be used in the screening program and the intended use of the information must be appropriate for accomplishing the purpose.
3. High-quality laboratory services must be used.
4. Individuals must be notified that screening will take place.
5. Individuals who are screened have a right to be informed about the results.
6. Sensitive and supportive counseling programs must be available before and after screening to interpret the results, whether they are positive or negative.¹⁷⁹

These early attempts to define ethical guidelines for screening programs emerged during a time that the "broad voluntarist consensus" had not yet developed in the United States. Thus, the guidelines were an effort to guide policy choices in an arena that was undergoing bitter dispute.

More recent proposals for guidelines have focused on the specific aspects of testing which continue to be debated. For example, there have been several recent proposals to expand routine hospital testing for HIV infection. In response, Brandt, Cleary and Gostin have proposed the following 3 guidelines for evaluating specific testing programs: (1) The test should be accurate; (2) The test should lead to effective action; (3) Patients must provide explicit consent to be tested.¹⁸⁰

So these guidelines were published in different political climates and with different policy goals in mind. Nonetheless, they have several important points of

agreement. These guidelines also share important similarities with WHO guidelines on screening programs, established in 1987.¹⁸¹ A distillation of these guidelines may therefore be used to evaluate the Cuban program of HIV testing.

The accuracy of the tests

One key point of agreement among the various proposed guidelines is that testing needs to be done with technical precision and accuracy. In general, those who advocate wider or more coercive testing programs tend to claim that currently available tests are extremely reliable in every respect (Cuban health officials fit in this group; more on this shortly). Conversely, critics of expanded or mandatory testing programs tend to highlight the possibility of error in the testing process.

However, some commentators on testing have avoided these patterned responses. Weiss and Thier, for example, argue that those who would oppose more widespread testing should not lean too heavily on the argument that the test is insufficiently accurate. For one thing, improvements in accuracy would "pull the rug out" from under such arguments; also, such arguments obscure other important ethical concerns about mandatory testing.¹⁸²

However, this is not to argue that questions of accuracy are unimportant in an ethical analysis of testing

programs. On the contrary, they are of the highest concern. The principle of beneficence demands that individuals not be subjected to any sort of harm (psychological, social, or whatever) as a result of receiving an avoidable false test result. For this reason, the question of accuracy merits more than the patterned responses often encountered from right-leaning and left-leaning analysts. What is needed is an objective and unbiased assessment of the quality of testing procedures.

In the Cuban case, it is especially clear that accuracy of the tests is an ethical issue. The consequences of a false positive result in Cuba are extremely serious - internment of an uninfected person. And it has been charged that Cuba's testing program does include a high number of false positives (between 8 and 20% of positive results in Cuba may be false, according to one account¹⁸³). So it is definitely worthwhile to take a close look at the question of testing accuracy.

The usual testing protocol in Cuba is very similar to that employed here. Blood samples are screened using the enzyme-linked immunoabsorbent assay (ELISA) method (in which purified viral antigens are used to detect a spectrum of anti-HIV antibodies in the person's serum). Samples that are repeatedly reactive to ELISA testing are subjected to confirmatory testing using a Western blot assay (which separates out the various antibodies into discrete "bands"

which may be seen on a strip of paper). Other tests such as the immunofluorescence assay are also available, but are less commonly used.¹⁸⁴ The central question, then, is the reliability of a testing sequence consisting of repeated ELISA assays followed by a Western blot confirmatory test.

Initially, Cuba bought testing materials from abroad, but they now make their own test kits, based on recombinant viral proteins. Cuba has sold its test kits to other countries (including Canada)¹⁸⁵, and has sent the kits to other countries and to the WHO for quality checks and comparisons.¹⁸⁶ Thus the quality of the tests is probably roughly comparable to what is available in commercial laboratories in the United States; it might even be superior, considering that recombinant viral antigens ought to be more pure than the viral antigens grown in human tissue-cell culture, which are used here. (Antigens derived from virus grown in human cell cultures have the potential disadvantage of containing extraneous human antigens, which may lead to cross-reactions and increased false positive results.)

Most estimates of the accuracy of ELISAs in the U.S. give a sensitivity of between 98 and 100%, and a specificity above 99%.¹⁸⁷ With any test, there is some tradeoff between sensitivity and specificity; the "set point" of the ELISA is usually such that a very high sensitivity is assured and very few true positives are missed (though more false

positives are "captured"). According to the head of the group which developed the Cuban tests, the accuracy in Cuba is similar - over 99% for both sensitivity and specificity are claimed, but the cutoff point is set such that the sensitivity is higher.¹⁸⁸

Of course, with a 99% specificity rate, 1 out of every 100 true negatives would be falsely labeled as infected. So using the ELISA alone would be highly unsatisfactory, as it would result in a very high number of false positive results (50,000 false positives in 5 million tests, for example). The sequence of tests, starting with repeat ELISAs and proceeding to the Western blot, is designed to reduce the inaccuracy to an acceptable level.

The accuracy of the standard series of tests (repeatedly reactive ELISAs followed by Western blot), even in the ideal laboratory, has not been firmly established. Different studies have yielded widely differing results on the accuracy of the standard series. In 1986 Gostin et al. calculated that the ratio of true to false positives with a single ELISA and follow-up Western blot, in a low prevalence population, would be approximately 70 to 1.¹⁸⁹ (It is important to recognize that any test has a greater likelihood of producing false positive results in a low-prevalence population.) Using this ratio, approximately 5 of the 356 Cubans labeled seropositive at the end of 1989 would have been falsely labeled as infected. However, this

does not take into account the requirement for repeatedly reactive ELISAs.

In 1987, the CDC calculated that the false positive rate for the standard sequence of tests, performed under optimal laboratory conditions on a low-prevalence population, would be between 1 in 100,000 and 5 in 100,000.¹⁹⁰ This would mean that having performed approximately 5 million tests by the end of 1989, the Cubans would have had between 50 and 250 false positives.

The same year, Gostin and Curran also predicted a gloomy result if the ELISA and Western blot assays were applied together in a low-risk population. They reported a 28% false positive rate (out of all positives) in this scenario.¹⁹¹ This would mean that almost 100 of the 356 people identified by the end of 1989 would have been false positives. However, it is not clear whether the sequence used in these calculations is the standard testing sequence.

The most recent studies on the standard sequence of tests, performed on low-prevalence populations under optimal laboratory conditions, have shown extremely high specificity (99.9993 to 100%).¹⁹² This translates to a false positive rate (out of all tests performed) of 0 to .0007%. In other words, out of approximately 5 million tests performed in Cuba through the end of 1989, up to 35 false positives may have been identified.

The long and the short of it is that there may well be

a serious problem of false positives in Cuba. Using different calculations of false positive rates has yielded several possible estimates of the total number of false positives in Cuba. The most recent studies may be the most accurate; calculations based on these rates suggest that up to 35 seropositives (approximately 10% of the total in Cuba) may have been falsely identified as such.

This is assuming that Cuban laboratory standards are at least as strict as those of U.S. reference labs, which may be an overly generous assumption, since several studies have shown that military, commercial and other labs in the United States often fail to live up to reference lab standards.¹⁹³ However, it should also be acknowledged that the recombinant technologies used in Cuba have the potential for superlative accuracy. Also, other methods of reducing inaccuracies such as repetitive sampling, use of immunofluorescence assays, etc., may be helping to hold down the false positive rate in Cuba. But the use and value of such measures remains to be proven.

I would conclude that the very real possibility of false positive results is a serious ethical pitfall of the Cuban mandatory HIV testing program.

Effective action and the purpose of the test

We have looked carefully at the ethical requirement that the test used should be accurate. What are some of the

other ethical guidelines for testing programs outlined above? One guideline that is common to several formulations is that the purpose of the test needs to be ethically acceptable, that is, the test needs to be employed to stop HIV infection and AIDS, and not for any more invidious use. Another way to express this is to state that effective action to control HIV or AIDS must be an integral part of any HIV antibody testing program. Brandt, Cleary and Gostin, for example, state that "routine use of the test can be justified only if the test leads to clear actions to prevent further transmission of the virus or specific clinical interventions in the interests of the patient."¹⁹⁴ This guideline is based on the principles of beneficence and respect for persons.

It appears on first glance that Cuba meets this criterion without difficulty, since the results of the tests are used BOTH to provide specific clinical interventions for HIV-infected persons and to attempt to prevent further spread of HIV. However, as discussed in chapter IV, invidious motives - such as social purification and stigmatization of infected persons - may well be tangled up with the scientific motives for testing and isolating. The principles of justice and respect for persons are violated by these uses of testing. But to criticize the Cubans on this basis involves constructing an argument based on perceived motives, since the Cubans claim that the only

intent of testing is to stop the spread of the virus.

The least restrictive alternative

Several formulations of testing guidelines demand a comparison of means and ends. Bayer, Levine and Wolf, for example, state that "the means to be used in the screening program and the intended use of the program must be appropriate for accomplishing the purpose."¹⁹⁵ Gostin, Curran, and Clark require that the least restrictive alternative of equivalent efficacy be employed. This guideline is based on the principles of justice and respect for persons.

The Cuban testing plan stumbles on this requirement. Government officials certainly claim that no less restrictive alternative would accomplish the same strict control of spread; they could appeal to the harm principle in making this argument. But their claim that the Cuban plan is effective has yet to be definitively proven, and the costs to individual autonomy within the Cuban plan are significant. So a mismatch between means and ends is a legitimate criticism of the Cuban plan.

Costs and benefits

A closely related guideline in the Gostin, Curran, and Clark formulation of testing guidelines is that "the critical consequences of screening should not outweigh

benefits."¹⁹⁶ As they explain, this guideline involves a judgement as to whether the health benefit of screening outweighs the costs to persons who test positive. The guideline is based on the principle of justice.

It appears fairly straightforward to condemn the Cuban testing plan based on this guideline. Unfortunately such a condemnation inevitably involves a discussion of differences in cultural values - the Cubans claiming that the greater good is highly valued in their culture, and that individual self-sacrifice is therefore a relatively minor cost. However, at the very least it can be demanded that this guideline requires an honest assessment of the costs of the Cuban plan, as perceived those who have tested positive. And as we have seen in earlier chapters, such an assessment is presently impossible, since access to the sanatorium is so highly restricted.

So even leaving aside the unsettled question of the public health benefits of the Cuban plan, the cost-benefit guideline clearly reveals that the Cuban plan is ethically suspect.

Autonomy and consent

One final sort of guideline remains to be considered. Several of the formulations described above demand that testing programs in some way respect the autonomy of the individuals to be tested, either by requiring explicit

consent before testing, or by ensuring confidentiality, or both. These guidelines are based on the principle of respect for persons.

There are no close judgement calls here; the Cuban plan clearly violates these guidelines. A defender of Cuba might point out that the ideals of individual autonomy are simply less important in Cuba than they are here. Certainly there are legitimate cultural differences in values between the U.S. and Cuba - but this does not imply (and few would argue) that the ideals of individual autonomy are of no importance at all in Cuba. Therefore, a wide-scale violation of these ideals needs to be explained and justified.

Utilitarianism in Cuba

As we have seen, the justification typically given for the abrogation of individual autonomy in the Cuban AIDS plan is that the greater good demands and outweighs it. In other words, a sort of utilitarian calculation takes place in which total pleasure and pain is tallied, and the pay-off in pain avoided by preventing infections weighs heavier than the pleasure that seropositives would feel if they were to maintain their autonomy and freedom. Does this line of thinking solve the problem of the violation of the autonomy guidelines? In other words, if it were proven that the Cuban AIDS prevention plan is drastically slowing the

epidemic, would this constitute a sufficient justification for the Cuban AIDS prevention plan?

I would argue that the answer is no. Purely utilitarian calculations are fraught with ethical pitfalls, for they allow a drastically unequal distribution of pain and pleasure, as long as the total amount of pleasure is maximized. Such calculations conflict with the principle of justice described earlier in this chapter, which requires that benefits and burdens of particular actions be distributed fairly. In the case of the Cuban plan of AIDS prevention, the consequence of a positive test (isolation) lays a heavy burden of pain on an innocent person. This conflicts with the principle of justice and is therefore ethically unjustifiable, regardless of the greater good rendered to society in the form of infections prevented.

Summary

It has been shown in this chapter that the Cuban plan of mandatory HIV antibody testing is in conflict both with basic principles of medical ethics and with commonly accepted guidelines on testing. One important concern is the possibility of inaccuracies in testing. There are also other issues. If the purposes of the testing program include the invidious motives of social purification and stigmatization of infected persons, then clearly the ethical basis of the program is suspect. Also, it remains to be

proven that the plan being followed is the least restrictive efficacious alternative. Finally, even if it could be proven that a cost/benefit analysis favors the Cuban program, such an analysis would be insufficient to justify the program on ethical grounds. The violation of the principles of justice and respect for persons renders such utilitarian calculations invalid.

VIII. QUARANTINE: AN ETHICAL ANALYSIS

No aspect of the Cuban AIDS program is more distasteful, or more widely disparaged, than the isolation of seropositives. In this chapter we will examine the issue of quarantine. First, some of the major objections to the use of quarantine to control AIDS will be considered, and placed within the Cuban context. Then follows a brief ethical evaluation of Cuba's quarantine plan.

The case against quarantine

It is startling to note how often critics of quarantine programs appeal to pragmatic concerns to make their case.¹⁹⁷ Mass quarantine is an absurd proposal, it is argued, because of the sheer numbers involved. Where would a million HIV carriers be isolated in the United States? Who would pay for such a mass relocation? How could such an enormous program be administered?

Such arguments are valid enough in countries with a high burden of HIV infection, but they hardly constitute a sufficient reason to reject quarantine in all circumstances. Concerns about the costs and impracticality of quarantine are far less significant in a country like Cuba, with its low seroprevalence rate. Indeed, the fact that prevalence is low in Cuba was precisely one of the reasons that quarantine was deemed feasible there.¹⁹⁸

One pragmatic argument does stand out somewhat from the

rest. This is the claim that any quarantine plan will backfire by driving seropositives "underground." In a general sense, it is undoubtedly true that there is a purely pragmatic danger in treating HIV-infected people harshly - it will be very difficult to then enlist their cooperation in halting the epidemic. But as has been shown in previous chapters, Cuba is for a number of reasons remarkably well situated to cope with this difficulty. For one thing, there is a high level of acquiescence to widespread testing. Also, there is a large amount of social control and contact with the state through the workplace, school, via medical providers, and so on. So the danger of driving AIDS "underground" is probably much less in Cuba than it would in most other countries if quarantine measures were introduced.

A somewhat more sophisticated kind of argument against quarantine is the historical approach. By looking at the history of quarantines for diseases such as leprosy, syphilis, cholera and tuberculosis, some have argued that quarantines have never worked in the past and therefore will not work in the case of AIDS.¹⁹⁹ The problem with this kind of argument is that the logical link is somewhat weak. It is undoubtedly true, for example, that a quarantine of cholera victims in New York in the 1830's was ineffective - but this was because cholera's causative agent and its mode of transmission had not been described. The situation today is vastly different.

This is not to say that the historical approach to discussing the contemporary quarantine problem is unhelpful. However, I would argue that the usefulness of such an approach lies not so much in predicting the epidemiological outcomes of present-day policies, as in helping to highlight the political and psychological functions which quarantines fulfill during times of social crisis and epidemic. Thus Guenter Risse, for example, argues that quarantines have been used to help to consolidate political or bureaucratic power, and as a "powerful tool to buttress social divisions and prejudices."²⁰⁰ Such observations are important, for they help to reveal some of the more invidious purposes which may underlie contemporary quarantine proposals or actual quarantine measures, such as Cuba's. However, such analyses do not by themselves prove that Cuba's quarantine policy is wrong.

Another kind of argument against quarantine as a means to stop AIDS states very simply that since the disease is not spread by casual contact, there is no technical reason to isolate. Some have taken this argument a step further and concluded that the quarantine policy in Cuba must be based on the most crazy irrationality, utterly divorced from any appreciation of the facts. But this is not the case. Cuban health planners are fully aware of the modes of transmission of HIV. The quarantine policy is specifically designed to prevent sexual contact (not casual contact)

between HIV positive and negative individuals.

Let's look a little closer at the argument that since HIV is not spread by casual contact, carriers should not be subject to quarantine. There are actually two assumptions behind this statement. The first is that it is customarily deemed necessary to quarantine people with highly contagious diseases who have no way of controlling their infectiousness. The second part is that it is ethically justifiable to quarantine such people. Now, are the converse two statements true? That is, is it definitely unnecessary and ethically unjustifiable to quarantine persons with other kinds of diseases? (Obviously, Cuban health planners don't think so.)

I would argue that although the first of the converse statements is debateable, the second is unquestionably true. In other words, it might be shown that quarantine of persons with HIV disease (or herpes, or whatever) could help to slow transmission (and in that sense such measures might be deemed "necessary"). However, such measures are definitely ethically unjustifiable.

In summary, it appears that the strongest arguments against the Cuban policy of quarantine are not the pragmatic, nor the historical, nor the technical, but the purely ethical considerations. These will be discussed further in the next section.

The ethics of quarantine

In the last chapter some basic principles of medical ethics were introduced. These included the principle of respect for persons, and the principles of harm, beneficence and justice. How can these principles be applied to the question of quarantine in Cuba?

A justification for quarantine can be constructed based on the principles of harm and of beneficence. The harm principle permits limitations to be placed on a person's liberty to pursue personal goals and choices when others would be harmed by those activities. The beneficence principle requires that public health authorities act in a way that maximizes the interests and welfare of all concerned.²⁰¹ It could easily be argued that Cuba's program of quarantine appeals to the harm principle in demanding sacrifice from a few in order to maximize the interests of all, which is the goal of the beneficence principle.

There are two (related) problems with this line of reasoning. One is that it is based on a utilitarian calculation. The second is that ignores a serious violation of the principle of respect for persons.

In the last chapter it was shown that ethical decisions based on purely utilitarian calculations are fraught with pitfalls, for they frequently distribute benefits and costs in a drastically uneven fashion. In this case, as we have seen, the costs of a policy are being borne almost entirely

by an innocent group of persons - who, it might be argued, should be the last ones to have to sacrifice for the sake of others, since they are already saddled with a heavy load of misfortune. Thus the purely utilitarian calculation violates the principle of justice.

The second problem with the justification for quarantine based on the harm principle is that it involves a serious violation of the principle of respect for persons. Sometimes, conflicts between the harm principle and the principle of respect for persons must be decided in favor the harm principle. For example, it is justified to restrict the autonomy of a person with a highly contagious and dangerous disease, for in this situation the person has little control over her contagiousness, and there are no other alternatives to protect other persons. But such is not the case with HIV infection. Any restriction of autonomy based solely on a person's HIV seropositive status is highly problematic, since it would have to be based on the assumption that in the future, the person would or might behave in an irresponsible manner. Clearly this assumption represents a grave violation of the principle of respect for persons, and a miscalculation of the balance between the harm principle and the principle of respect for persons. Most people would agree that it is ethically unacceptable to punish a person in advance for a crime you suspect she may commit some time in the future.

Summary

This chapter has looked at the cornerstone of the Cuban AIDS plan: quarantine of seropositives. The discussion of this matter has been brief, but perhaps this is appropriate, since the main pitfall of the policy is the readily apparent violation of ethical standards which it entails.

IX. SUMMARY AND POLICY RECOMMENDATIONS

This paper has attempted to examine with fairness and objectivity some of the many aspects of the Cuban program of AIDS prevention. We have looked at some of the many reasons for Cuba's unusual plan - some of which are rooted in Cuba's uniqueness, and some of which spring from its common human weaknesses. We have seen that the Cuban plan may be working - but that advocates of the plan have tilted the evidence in their favor. We have looked closely at the pragmatic and ethical pitfalls of the Cuban plan, and have concluded that they are serious, and troubling. But we have also seen that critics of the plan have frequently misunderstood and even distorted it.

Politics and medicine

At the beginning of this paper three quotes appear. The first is probably the best-known quotation of the famous German pathologist Rudolf Virchow: "Medicine is a social science, and politics nothing but medicine on a grand scale."²⁰² The long tale told in this paper is a prime example of Virchow's dictum. It is a tale which underscores the point that health care is a deeply political exercise, and that issues of crucial clinical significance cannot be solved without an understanding of the complexities of international and national politics.

Cuban society

The second quote is from Jonathan Mann, former director of the WHO's Global Program on AIDS, who states that "One of the most remarkable features of the pandemic of HIV infection and AIDS is a relentless capacity to focus attention on long-standing, complex and unresolved social issues."²⁰³ This quote is a poignant summary of some of the lessons of the Cuban tale, for much of what we have seen does illustrate a complex tangle of unresolved social issues within Cuban society. These issues include such things as the unfulfilled promise of greater democracy; the long-term struggle over social problems such as homophobia; and the complex problem of a highly paternalistic, yet popular health care system which instinctively imposes aggressive solutions on a habitually passive public. Ultimately, a solution of the contradictions and serious ethical flaws of the Cuban AIDS plan will depend on a resolution of these important problems within Cuban society.

Flexibility of perception

The third quote is from a story by the Argentinean writer Julio Cortázar. It roughly translates: "every act of looking oozes with mendacity, because it is that which propels us furthest outside ourselves."²⁰⁴ I won't comment on this observation except to note the tremendous difficulty and supreme importance of reaching beyond the assumptions of

one's own culture and one's own political system to attempt to see and understand the workings of another society.

Policy Recommendations

I would like to end this paper by expressing the hope that Cuba will live up to the ideals of its health system, and overcome the barriers which presently prevent the just treatment of people exposed to the human immunodeficiency virus.

CHAPTER I NOTES

1. Panos Institute, AIDS in the Third World, p. 1.
2. *ibid.*, p. 2.

CHAPTER II NOTES

3. See Danielson (1979), Ch. 6.
4. Danielson (1979), p. 116.
5. Santana (1987), p. 113.
6. Santana (1987).
7. See Werner (1978), who stresses this point, but also Navarro (in the NEJM 1972), p. 958, who mentions this in the context of a very sympathetic account of Cuban health care. Also Stein and Susser (1972), p. 559.
8. Santana (1987), p. 117.
9. Marta Rojas, El Medico de la Familia en la Sierra Maestra, (Ciudad de La Habana: Centro Nacional de Información de Ciencias Médicas, 1986), ch. 2.
10. Margaret Gilpin, "Cuba: On the Road to a Family Medicine Nation," photocopy of a paper submitted to Family Medicine, p. 19.
11. See for example responses to Ubell (1983), in the New England Journal of Medicine, July 5, 1984, pp. 60-61; Cuban American National Foundation (1988).
12. Navarro (IJHS, 1972), p. 407.
13. See the "Note on the quality of Cuban health statistics" following Santana (1987), p. 125.
14. Werner (1978), pp. 29-30.
15. Santana (1987), p. 121.
16. Werner (1978), p. 31. Italics in original.
17. See Danielson (1979), ch. 4.
18. Danielson (1979), p. 121.
19. Danielson (1979), p. 139.
20. For an extensive critique of the limitations on popular input into health policy, see Werner (1978).

CHAPTER III NOTES

21. Werner (1978), p. 2.

22. An early summary of Cuban AIDS policies may be found in the first official published statement on AIDS from the Cuban government: GRANMA April 17, 1987. "Información del ministerio de salud pública sobre el programa de lucha para la prevención del síndrome de inmunodeficiencia adquirida (SIDA) en Cuba." See also the Guardian (Oct. 28, 1987), The Washington Times (May 8, 1987) and The Miami Herald (Sept. 17, 1987). Some information here is also from personal communications with MINSAP officials in Havana.

23. GRANMA April 17, 1987. "Información del ministerio de salud pública sobre el programa de lucha para la prevención del síndrome de inmunodeficiencia adquirida (SIDA) en Cuba." [Translation by VB]

24. *ibid.*

25. *ibid.*; paraphrased.

26. *ibid.*; paraphrased.

27. Enrique Galbán García, national epidemiologist with the Ministry of Public Health, Havana, Cuba. Personal communication.

28. Guardian (Oct. 28, 1987).

29. Washington Post (March 22, 1987).

30. Cf. San Jose Mercury News Feb. 25, 1987, "More AIDS Cases in Cuba;" Washington Post March 22, 1987, "Cuba Accused of Cover-Up on Prevalence of AIDS;" Washington Times April 16, 1987, "As prices, shortages, AIDS plague Cuba, exodus builds."

31. See Cord Meyer, Washington Times May 8, 1987. "Cuba's AIDS Dilemma."

32. Granma April 17, 1987. "Información del ministerio de salud pública sobre el programa de lucha para la prevención del síndrome de inmunodeficiencia adquirida (SIDA) en Cuba." See also reports in the New York Times (April 18 and 19, 1987).

33. Granma April 17, 1987. "Información del ministerio de salud pública sobre el programa de lucha para la prevención del síndrome de inmunodeficiencia adquirida (SIDA) en Cuba." [Translation by VB]
34. cf. Guardian, Oct. 27, 1987. "Health Official details drastic approach to AIDS," by Karen Wald.
35. Hector Terry, as quoted in "Village Voice questionnaire [sic] re: AIDS," (photocopy, distributed 8/89) prepared by Karen Wald.
36. Ronald Bayer and Cheryl Heaton, "Controlling AIDS in Cuba, the Logic of quarantine." Photocopy, dated Nov. 11, 1988.
37. cf. letter from H. Daniel to Fidel Castro, New York Review of Books, Oct. 26, 1989.
38. Karen Wald, (U.S. journalist who lives in Havana), personal communication, 8-11-89.
39. Dr. Jorge Perez, Personal communication, May 1989. See also Ciro Bianchi, "Una Apuesta con el SIDA," Cuba Internacional, Sept. 1989.
40. Ciro Bianchi, "Una Apuesta con el SIDA," September 1989, p. 20.
41. Ciro Bianchi, "Una Apuesta con el SIDA," Cuba Internacional, September 1989.
42. Granma, May 19, 1989, "SIDA en la agenda científica," por José de la Osa.
43. MINSAP figures, quoted in S.F. Chronicle, Nov. 25, 1989, "Half of all Cubans have received AIDS screening," and in Granma, Dec. 10, 1989, "On the frontiers of AIDS," by Carlos Cabrera.
44. Dr. Jorge Perez, director of the Pedro Kouri Tropical Medicine Institute in Havana - personal communication, May 1989.
45. Guardian, Oct. 27, 1987.
46. Dr. Caroline L. MacLeod, director of the Tropical Medicine Institute in Miami. Quoted in the Washington Post, March 22, 1987.

47. Latest statistics are from Granma, Dec. 10. 1989. The male:female ratio has been about 2.7:1 for a couple of years.

48. MINSAP figures quoted in Cordoves (1989).

49. See for example the letter in the New York Times, Jan. 3, 1989, from Jeanne Smith, M.D. and Sergio Piomelli, M.D., two hematologists who accompanied Ron Bayer on his visit to Cuba in Oct. of 1988.

50. Dr. Enrique Galbán García, personal communication ("Another important thing is that in Cuba, there are no IV drug addicts. I can affirm this categorically, and it's not a communist exaggeration. It just doesn't exist.") However, others have speculated that the drug trafficking scandal involving top-level Cuban officials in the summer of 1989 implies that there may have been some leakage of these drugs into the Cuban interior. There is certainly little evidence of such leakage.

51. Granma Dec. 10, 1989.

52. Source of figures; MINSAP, quoted in the following sources: Granma, Bohemia, PAHO bulletin, and Cuba Internacional.

53. *ibid.*

54. For example - Granma June 28, 1986: "Testimonio de Transmisión," por José de la Osa.

55. Sierra Wald, personal communication, August 1989.

56. Karen Wald, personal communication. August 1989.

57. Dr. Jorge Perez, personal communication. May, 1989. Excuse the bad English. The interview was conducted in English.

58. Granma, Feb. 20, 1988. "La mejor arma contra el SIDA sigue siendo la educación," por José de la Osa; Cuba Internacional, September 1989, "Una Apuesta con el SIDA," por Ciro Bianchi.

59. Susan ML Laver, "African Communities in the Struggle Against AIDS: the Need for a New Approach," in Fleming, A. et al., eds. The Global Impact of AIDS. New York: Alan R. Liss, 1988, p. 282.

60. Karen Wald, personal communication, August, 1989. See also Bayer's discussion of his interviews with Hector Terry in Los Angeles Times, November 4, 1988: "Cuba's AIDS Quarantine Center called 'Frightening'," by Victor Zonona.

61. Ernesto Betancourt (1988). (Betancourt is executive director of Radio Martí, which is funded by the U.S. government).

62. Cited, for example, by Wald (personal communication) and Perez (personal communication). See also Ciro Bianchi (Sept. 1989).

63. Karen Wald, personal communication, August 1989.

64. Bayer and Healton (1989) p. 1024.

65. Dr. Enrique Galbán García, personal communication.

66. Granma Dec. 10, 1989.

CHAPTER IV NOTES

67. Navarro (NEJM, 1972). Note, however, that Navarro's article was written before the heyday of 'poder popular' and before the family doctor program was started.
68. Tesh (1986), p. 91.
69. Ibid., p. 94.
70. This assumes that AIDS is not a genetically engineered disease, a thesis which has not been disproven to my personal satisfaction, but which seems to me unlikely in comparison to the widely held view that AIDS is an invention of evolution.
71. Guardian (Oct. 28, 1987).
72. Ibid.
73. Dr. Galbán García, personal communication.
74. Monika Kraus, director of the national group on sex education, speaking in the film "No porque lo diga Fidel."
75. See Stephen Risch and Randolph Wills, "Positive Views of Gays," (1980).
76. Much of the debate has coalesced around the 1984 film Improper Conduct by Nestor Almendros. Discussions of the film appear in the Village Voice July 24, 1984 & August 14, 1984 and in Cuba Internacional December 1984. See also Judy Ornstein's piece "Gay Cuba" in the New York Native August 18, 1986.
77. One piece of evidence of excruciatingly slow yet perceptible progress is the following. While visiting a psychiatric hospital in Manzanillo in March of 1989, a group of U.S. doctors was given complimentary copies of the Cuban version of the DSM-III, entitled Glosorio Cubano de la clasificación internacional de enfermedades psiquiátricas, printed in 1986. This little volume lists homosexuality as a disorder, under the classification of sexual deviations. When questioned about this entry, the psychiatrists at the hospital explained that they no longer considered homosexuality a disease, and that there had been delays in the preparation of a new edition of the glossary, which would reflect this new view.
- See also Fee (1988), "An interview with Dr. Celestino Alvarez Lajonchere."

78. Sabatier (1987).

79. This problem may be getting better. An article on Los Cocos in Granma in December of '89 showed the faces of the residents.

80. Boston Globe June 29, 1986. "She'll return to Cuba without dead son, a victim of AIDS," by Eduardo Paz-Martinez.

81. Sontag (1989), p. 65.

82. Ibid., p. 62.

83. Guardian, Oct. 27, 1987.

84. Richard D. Mohr, "Policy, Ritual and Purity: Gays and Mandatory AIDS Testing." Law, Medicine and Health Care Vol. 15 #4 (Winter 1987/1988), pp. 178-185.

85. See Mohr (1987/1988) for a full discussion of mandatory testing as a social purification ritual.

86. Danielson (1979).

87. Guttmacher (1987), p. 179.

88. Bianchi (Sept. 1989), p. 24. Translation by the author.

89. Dr. Enrique Galbán García, personal communication, May 1989. [translation by VB]

90. Karen Wald, personal communication, August 1989.

91. Bill Rowe, professor of anthropology from the University of Minnesota, as quoted by Karen Wald, August, 1989.

92. Cuban American National Foundation (1988), p. 4.

93. *ibid.*, pp. 4-5.

94. SF Chronicle, April 25, 1989, "How Cuba places AIDS patients in quarantine," by Robert Collier.

95. For example: Wald, personal communication, August 1989; Bianchi (1989).

96. Santana (1989).

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97. See for example Von Reyn and Mann (1987); Lambert (1989).
98. Does anybody besides me think it is just TOO MUCH that the United States and Europe get to be pattern 1, while Africa, where AIDS supposedly originated (according to many U.S. and European scientists), is designated pattern 2? Just thought I'd point that out.
99. Piot et al. (1988), p. 576.
100. Jonathan Mann, James Chin, Peter Piot and Thomas Quinn, "The International Epidemiology of AIDS." in Piel, ed., The Science of AIDS (1989), p. 53.
101. Sato, Chin and Mann (1989), p. S304.
102. Ibid.
103. Ibid., p. S303.
104. According to the director of the national center for AIDS information. Guardian July 15, 1987. "Administration provides enlightened AIDS education," by Gray Newman.
105. In These Times, July 22, 1987. "AIDS is endemic in a Mexican slum," by Mike Tangeman.
106. San Francisco Chronicle, June 7, 1988, "The AIDS Epidemic in Brazil," by Tyler Bridges.
107. Sato, Chin and Mann (1989), p. S304.
108. Jai P. Narain, B. Hull, et al., "Epidemiology of AIDS and HIV Infection in the Caribbean." PAHO Bulletin (1989), p. 46.
109. Panos (1989), pp. 176-179.
110. Ibid., p. 118-119.
111. Heise (1988), p. 26.
112. Susan Scholle Connor, "AIDS: Social, Legal, and Ethical Issues of the 'Third Epidemic'." in Bulletin of the Pan American Health Organization (1989), p. 95.

113. Ibid.

114. Quoted from WHO documents in Panos (1989), p. 105.

115. Ibid.

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116. Granma April 17, 1987. [Translation by VB.]
117. Granma, Sept. 27, 1987.
118. A.R. Moss & P. Bacchetti, "Natural History of HIV infection," (1989).
119. Robert Redfield and Donald S. Burke, "HIV Infection: The Clinical Picture," in The Science of AIDS (1989), pp. 71.
120. 1988 figures from Terry et al (1989), p. 64; 1989 figures provided during interviews with Dr. Galbán García, May 1989.
121. MINSAP figures published in Bohemia in February of 1989 state that the mean survival time of patients is 16 months, with a range of between 9 and 30 months. However, the starting point of these calculations is not stated, which makes comparisons difficult. Average survival time following diagnosis of AIDS in the U.S. has been increasing; from 10.1 months in previous years to 13.9 months (1989 calculations). (Source: Harvey S. Bartnof, M.D., "Overview & Introduction: Why AIDS?" - syllabus for course at UCSF, typewritten manuscript.)
122. Granma, Sept. 18, 1988.
123. Centers for Disease Control, "Revision of the CDC surveillance case definition for acquired immune deficiency syndrome," MMWR 36 (Suppl. 1): pp. 1S-15S, 1987.
124. All are MINSAP figures. (1) Granma; (2) WHO, in PANOS documents; (3) PAHO; (4) Bohemia; (5) Reuters.
125. Lair Guerra de Macedo Rodrigues & Pedro Chequer, "AIDS in Brazil, 1982-1988," from Bulletin of the Pan American Health Organization (1989), pp. 30-34.
126. Paul Sato, James Chin and Jonathan Mann (1989).
127. See for example Granma Sept. 18, 1988.
128. Hector Terry M., quoted in Bianchi (1989).
129. Calculated from MINSAP figures gathered from several sources.

130. See for example the debates regarding geometric progressions and normal growth curves in Bulletin of the Pan American Health Organization (1989).
131. José Luis Valdespino G., et al. "AIDS in Mexico: Trends and Projections," in Bulletin of the Pan American Health Organization (1989), pp. 20-23.
132. Jorge Boshell S., et al, "AIDS in Colombia," in Bulletin of the Pan American Health Organization (1989), pp. 24-29.
133. Lair Guerra de Macedo Rodrigues & Pedro Chequer, op. cit.
134. Thomas C. Quinn, et al., (1989), p. 191.
135. Santana (1989), p. 25.
136. Personal communication, May 1989.
137. Cordoves (1989).
138. Sept. 18, 1988.
139. Terry et al. (1989), p. 65.
140. Cordoves (1989).
141. Raw data from Cordoves (1989). Rates are calculated.
142. Raw data from Cordoves (1989). Rates are calculated.
143. Raw data from Cordoves (1989). Rates are calculated.
144. Dr. Enrico Delano (province of Bayamo), personal communication.
145. Panos Dossier (1989), p. 136.
146. Thomas C. Quinn, et al. (1989), p. 190.
147. e.g., Nicaragua, the British Virgin Islands, Montserrat. See PANOS dossier (1989).
148. See for example Washington Times, May 8, 1987. "Cuba's AIDS Dilemma," by Cord Meyer.
149. Ron Bayer, personal communication, July 1989.
150. Bayer and Heulton (1988), p. 5.

151. Dr. Terry, quoted in Bianchi (1989), p. 23.
152. Maria Se Medina et al. (1987).
153. Gordon (1987); Gordon and Paya (1989).
154. Gordon (1987).
155. Bayer and Healton (Sept. 21 1989).
156. Terry et al. (1989), p.67.
157. Cordoves 1989.
158. Peter Piot et al., 1988, p. 577.
159. See Bernard Lo, Robert Steinbrook, et al. (1989), p. 728.
160. Bayer and Healton (Sept. 21, 1989).
- ✓ 161. New York Review of Books, Oct. 26, 1989, "AIDS in Cuba," letters from R. Bayer and H. Daniel.
162. Santana (1989) describes the uneventful refusal of "dozens" of persons to be tested during general-population screenings; she claims there were no reprisals and no forced testing, although peer pressure to be tested is very strong.
163. New York Times Feb. 6, 1989.
164. Bayer and Healton (1988), p. 12.

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165. WHO, "Criteria for HIV Screening Programs," from Bulletin of the Pan American Health Organization 23 (1-2), 1989, p. 176.

166. Ibid.

167. Connor (1989), p. 99.

168. American College of Physicians, Health and Public Policy Committee. (1988), p. 464.

169. Gostin (1987), p. 14.

170. Ibid.

171. See Bayer, "Ethical and social policy issues..." (1989), p. 119.

172. Rhame and Maki (1989), p. 1248. See also American College of Physicians (1988).

173. Bayer, "Ethical and social issues..." (1989), p. 121.

174. See for example Katz (1989), quoting World AIDS.

175. Karen Wald, personal communication, Aug. 1989.

176. Santana (1989), p. 23.

177. Bayer, Levine and Wolf (1988), pp. 176-177.

178. Bernard Lo, Robert L. Steinbrook, et al., (1989), p. 727.

179. Bayer, Levine, and Wolf (1987), pp. 177-178.

180. Allan M. Brandt, Paul D. Cleary, and Lawrence O. Gostin, "Routine Hospital Testing for HIV: Health Policy Considerations." in Gostin, ed. AIDS and the Health Care System (1990), pp. 127-129.

181. WHO, "Criteria for HIV Screening Programs." Bulletin of the Pan American Health Organization Vol. 23, Nos. 1-2, 1989, pp. 176-182.

182. Robin Weiss and Samuel O. Thier (1988), p. 1010.

183. Bayer and Healton (1989), p. 1023.

184. Dr. Galbán of MINSAP, personal communication.
185. S.F. Chronicle, Nov. 25, 1989, "Half of all Cubans have received AIDS screening," Reuters.
186. Santana (1989); Village Voice (Feb. 14, 1989).
187. Examples: MMWR (Aug. 14, 1987); T. Gregory, ed., "HIV testing and patient counseling." (1989), p. 26; American College of Physicians (1988), p. 464.
188. Granma April 9, 1989.
189. Gostin, Curran and Clark (1986), p. 35.
190. CDC, MMWR, Aug. 14, 1987.
191. Larry O. Gostin and William J. Curran, "Seriousness of AIDS and Screening," (1987).
192. See Gregory (1989), p. 27; Weiss and Their (1988), p. 1010.
193. See Lo, Steinbrook et al., (1989).
194. Brandt, Cleary and Gostin, (1990), p. 128.
195. Bayer, Levine and Wolf, p. 177.
196. Gostin, Curran, and Clark (1986), p. 23.

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197. See for example Panos (1989), p. 121.

198. See Hector Terry's comments in the Guardian (Oct. 28, 1987).

199. David Musto, "Quarantine and the Problem of AIDS," in AIDS: the Burdens of History, ed. by Elizabeth Fee and Daniel Fox. (Berkeley: University of California Press, 1988), pp. 67-85.

200. Guenter B. Risse, "Epidemics and History," in AIDS: the Burdens of History, ed. by Elizabeth Fee and Daniel Fox. (Berkeley: University of California Press, 1988); pp. 33-66.

201. Bayer, Levine and Wolf (1988), p. 177.

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202. Quoted, for example, in James Trostle, "Early Work in Anthropology and Epidemiology: From Social Medicine to the Germ Theory, 1840 to 1920," in Janes et al., eds. Anthropology and Epidemiology, p. 45.

203. Jonathan Mann, "AIDS and Health Care Workers from a Global Perspective," in AIDS and the Health Care System, Lawrence O. Gostin, ed. (1990), p. 233.

204. Julio Cortázar, from his story "Las babas del diablo," which appears in the anthology Las armas secretas (Madrid: Ediciones Cátedra, 1989), p. 128.

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