Public health

AIDS, public health, and human rights in Cuba

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Cuba is the only nation that has incorporated elements of the classical public health tradition—routine testing with contact tracing and partner notification and close medical surveillance and partial social isolation of all infected individuals—in a national programme to contain AIDS. With only 927 cases of HIV seropositivity (as of May 31, 1993) and only 187 cases of AIDS (with 111 deaths) in a population of over 10 million the policy seems to have succeeded. Cuba's immediate neighbours—but especially Haiti, the Bahamas, and Barbados—have cumulative prevalence rates for AIDS similar to, or greater than, those of United States. Puerto Rico, with one-third the population of Cuba, has over 8000 cases of AIDS, 208 of them in children. In Cuba only 1 child had died of AIDS; 3 more carry the virus. In New York City, with roughly the same population as Cuba, 43 000 patients have AIDS, and in the United States as a whole, there are more than 1000 paediatric AIDS cases. In France and Brazil thousands of people have been infected with HIV contaminated blood and blood products; only 9 Cubans have been infected through a transfusion.

Many factors have contributed to the control of AIDS in Cuba, apart from its controversial public health programme; the absence of intravenous drug use, a climate of sexual puritanism and of hostility (leading to an exodus of gay Cubans), and easy access to abortion.

Moreover, Cuba had an excellent health system already in place so officials could act promptly and decisively. AIDS was never handled in Cuba (as it has been in most western democracies) as a "special case", to be treated gingerly for fear of offending high-risk populations. It was viewed there as just another major threat to public health and health officials see every Cuban AIDS case as unnecessary. Their AIDS policy is modelled on socialist rational planning and flies in the face of the political spirit of the times in the rest of the world.

The Cuban AIDS programme has been criticised for its violation of the privacy and freedom of seropositive people. Most of the criticism has focused on the isolation of people in sanatoria and little attention has been paid to the equally severe policy of recommending abortion when any pregnant woman tests HIV positive. Cuban health officials remain uncowed by criticism: Cubans, they say, are not dying of AIDS. The international community remains unimpressed: in place of the aphorism "the operation was a (technical) success but the patient died" one hears it said that Cubans may not be dying of AIDS but the operation is a (moral) failure.

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However, international researchers who have visited the Cuban sanatoria and reviewed the medical records and quality of care have been impressed. Even as dogged a critic of the Cuban model as Dr Jonathan Mann, former director of the WHO AIDS programme, noted his favourable impression on the first page of the visitor's book at the Havana sanatorium. But outsiders still judge the Cuban programme an anachronism in the civil libertarian climate of late 20th century.

In June, 1991, I went to Cuba where I met with Dr Hector Terry, vice-minister of the Cuban Ministry of Public Health, and visited the Santiago de las Vegas sanatorium on the outskirts of Havana. In May, 1993, I returned. Between these two trips I invited the director of the AIDS sanatorium, Dr Jorge Perez, to the University of California, Berkeley and co-sponsored a visit to the Bay Area of San Francisco by two sanatorium patients, both Cuban AIDS activists. I remain impressed. (The clinical and epidemiological data are available for review by any independent professional panel including the US Centers for Disease Control and WHO.) The human rights issue does need to be debated but Cubans seized the moment, at the very start of the epidemic, when they had 40 000 troops returning from highly infected parts of central Arica, and managed to contain AIDS. Consequently, the AIDS tragedy one finds in Haiti or Brazil was averted, and this remarkable public health acomplishment must not be lost sight of.

Cuba's AIDS programme

The AIDS policy has evolved through trial and error. When Cuban officials learned of the AIDS epidemic, after a Pan American Health Organization meeting in 1983, the first thing they did was ban the importation of blood derivatives from countries where AIDS existed and where blood banks were commercially owned ("capitalist blood"). When commercial tests for HIV antibodies became available in 1985, the government started to test all Cubans who had been out of the country since 1981. Among those found seropositive were a large number of Cuban soldiers ("internationalists") returning from Africa. By June, 1986, testing had been extended to all blood donors and to those whose work involved extensive travel, such as tourist and resort and airline workers, fishermen, and sailors. When the first Cuban diagnostic kits became available in 1987, HIV screening was extended to all pregnant women, all those with sexually transmitted diseases, and all inpatients and prisoners. Later, entire neighbourhoods in tourist locations, such as Old Havana were screened. In 1985 a special group was set up to trace and test, regularly and repeatedly, the sexual partners of all seropositive persons. For every seropositive there is a confidential sexual contact tree that traces the spread of HIV infection through sexual partners, all of whom are contacted and screened.

Cuba's is the most comprehensive HIV screening programme of any nation. Screening is routine in Cuba's health system, and the HIV test was merely added to the work-ups to which workers and students have long been accustomed. 12 million HIV tests have

been done in Cuba and the results indicate a very low prevalence of seropositivity and fewer than 125 new cases each year.

In Cuba, in the absence of intravenous drug use and contaminated blood, seropositivity in an adult indicates infection via sexual activity but AIDS is not viewed as a disease of the sexually stigmatised. Over 60% of seropositive Cubans are heterosexuals, many of whom were infected overseas on military duty or on foreign assignment as doctors, nurses, and laboratory technicians or were the sexual partners of such people on their return. AIDS tends to be viewed in Cuba as an occupational hazard of internationalists, and these are hardly a stigmatised population.

AIDS sanatorium

In 1986 Cuba embarked upon its most controversial AIDS programme when it opened the Santiago de las Vegas sanatorium with a mandate to evaluate, treat, and observe HIV-positive individuals. The point, Cuban health officers argue, was never quarantine (which makes no medical sense since HIV is not an airborne virus) but aggressive medical treatment, research, testing of new drugs, and epidemiological surveillance. The primary goal was therapeutic, and protection was secondary. However, any sanatorium is an odd blend of care and coercion, and during an epidemic its doctors have two "patients"—the infected individual, who needs compassion and care, and the community, which must be protected.

At first, the sanatorium was run by the military for soldiers from Africa who were believed to be the primary reservoir of HIV. By all accounts the first sanatorium was an ugly medicalised army barracks. Patients could not leave the grounds and armed guards stood at the gate. Little was then known about the transmission of AIDS and its incubation period, and many of the first soldiers to arrive thought that they had a strange variant of hepatitis B.

Later in 1986 the military doctors became perplexed by the growing number of civilians, most of them homosexuals, who tested positive in their neighbourhood clinics and began arriving at the sanatorium. Conflict arose between these new arrivals and the defensively homophobic soldier patients, so that the first dozen homosexuals had to be segregated from the soldiers and were discriminated against in terms of recreation and privileges. The inmates were not passive, however, and pressed for reforms. When it was recognised that the transmission of HIV required more than casual contact, residents were permitted to leave the sanatorium accompanied by a chaperone, usually a medical student. In 1987 the military handed responsibility over to the Ministry of Public Health and the sanatorium was transformed from a barracks into a community. After Dr Perez was appointed medical director (figure 1), a new system allowed all "trustworthy" or "guaranteed" patients to return home unaccompanied for weekend or even week-long visits with a view to the day when they would return home permanently. From the start Perez questioned the medical justification for keeping the vast majority of trustworthy residents permanently at the sanatorium.

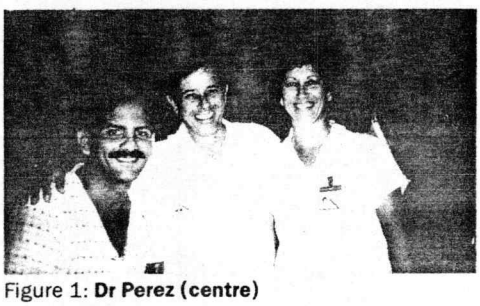

Figure 1: **Dr Perez (centre)**

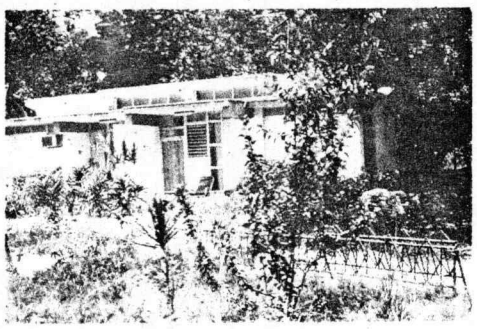

Figure 2: **Unit in grounds of rebuilt sanatorium**

The old buildings were destroyed and a modern housing complex built in its place; today Santiago de las Vegas is a suburban community of several acres dotted with modern, one and two storey apartments surrounded by lush vegetation, palm trees, and small gardens (figure 2). The old wall has been demolished for in this face-to-face community—where doctors, epidemiologists, and residents are known by their first names and where permission to leave the grounds is rarely denied—locks and keys are not the point. But permission to leave must still be sought and this angers some residents. And the sanatorium still has its rules. All new residents undergo a six month probationary period before achieving the status of "guaranteed", a patient who can spend weekends and some weekday nights at home. To be guaranteed a panel of doctors, epidemiologists, and psychologists must be convinced that the resident understands and accepts that he or she is carrying potentially fatal, transmissible disease and that they have a moral obligation to see that no other person contracts it from them. About 80% of residents achieve that status after the probationary period.

Every patient has to respect the three "commandments" of the sanatorium: (1) to have unprotected sex with an unknowning, uninfected individual is murder; (2) to have unsafe, but consensual sex, with an uninfected partner is criminal; and (3) to have unprotected sex with another infected partner is mutual suicide. Safe sex is the right of every resident, and there is no policing of sexual activity. "We do not follow residents into their bedrooms", the medical director told me. The surveillance is indirect and largely epidemiological.

Residents behaving irresponsibly lose their right to leave the sanatorium unaccompanied. One resident seduced a young girl he met when on a weekend leave. He told her that he was from the AIDS sanatorium but she was infatuated and refused condoms. Now she too is in the sanatorium nursing her dying boyfriend. He is full of remorse; she is not but, as a foolish 16-year-old, death is very far from her thoughts.

It has been suggested that many seropositive Cubans are in hiding to avoid testing and the sanatorium. However, Cuba's health care services intrude on all levels of private and public life. There is a family doctor for every dozen apartment blocks. These doctors live in the neighbourhood and spend a good part of the day in the homes of the families. They know every family intimately. All Cubans eventually come into contact with the medical system in their neighourhoods or at work, in school or day care centres, or in polyclinics, and medical testing of all kinds is routine.

Although some Cubans I met good-humouredly described doctors as "inescapable", medicine is generally viewed as benevolent, even by those dissatisifed with many other aspects of Cuban life. And Cubans in general, gays as well as heterosexuals, strongly support the AIDS programme. But there was also sympathy for the men and women detained at "Los Cocos" for "the common good".

Cuba's universal health and welfare system eliminates two problems that come with HIV status in the United States. Sanatorium residents are paid their full, regular salaries, whether

they work or not. (Almost half of them do work, inside the sanatorium or outside.) Some take university classes or tend their homes and vegetable gardens or tinker with old cars and broken machines in makeshift body shops.

All residents are treated with individually tailored regimens including interferons, transfer factor, and low-dose zidovudine. Those who do not respond well or who prefer alternative medicines are offered one of several antiviral herbal medicines currently being tested at the sanatorium. A small infirmary handles patients with AIDS-related illnesses but the very sick are transferred to the Medical Institute for Tropical Medicine in Havana, where they are cared for with patients suffering from other serious communicable diseases. Exercise and a diet rich in calories (5000 kcal daily) and protein are integral parts of the regimen—indeed sanatorium residents are better fed than the average Cuban worker and each one costs the Cuban state about $15 000 a year.

Beginning in 1990, the director began an experiment that returned a dozen guaranteed patients to their communities. This proved successful and at the beginning July, 1993, the sanatorium began a more open programme. There is still a six-month probationary period but all guaranteed residents may then return home or stay at the sanatorium, as they wish. This announcement did not produce the elation and relief among sanatorium residents that one might have expected. Cuba faces an economic, oil, and food crisis and life outside the sanatorium is hard with food rationing, overcrowding, power failures, and competitive family tensions from which residents have been insulated.

Bringing it all back home

Both times I returned from Cuba with contradictory impressions and many questions. When is "good medicine" altogether too much and too bitter a pill to swallow? Under what conditions is a medical policy as restrictive of individual human rights as Cuba's ethically warranted?

Cuba is not a huge concentration camp hiding a terrorised population. Nor is it a tropical utopia. There are severe shortages, poor communications, and poor transporation, and Cuba has a lumbering bureaucracy and is an authoritarian state. But this island has the most developed health care system in the third world. The young and the old are healthy and well-fed, infant mortality is exceptionally low, and everyone is housed and clothed. But medicine there is an arm of the state, and medical surveillance hints at bodies too readily disciplined, examined, and medically treated.

There is abundant evidence, in the longevity of AIDS sanatoria residents and in the low incidence of seropositivity, that Cubans may have achieved protection from AIDS by the very methods rejected in the United States and by the WHO AIDS programme as violations of individual rights. Facile ideological criticism of the Cuban approach seems out of place but if the same result could have been accomplished without the sanatorium system Cuba has violated the rights of its seropositive citizens and restitution can never be made.

In the United States and Europe human rights issues were seen as central from the very start of the epidemic. Arriving as it did on the heels of the sexual revolution and the feminist, gay rights, and patient's rights movements, AIDS was seen as a major test of our commitment. It differed from previous epidemics in the extent to which members of the afflicted communities played an active part in limiting the public health response. Social and political agendas were in place before the basic facts about the epidemic were known. In Cuba initial ignorance about transmission resulted in a panicky isolation of all seropositives but in the US the rights agendas already in place provoked a "hands off" response so virulent we lost sight of the real threat. As Stephen Joseph, former Commissioner of Public Health for the City of New York told me in May, 1993 "We came to think of AIDS as fundamentally a crisis in human rights that had some public health dimensions, rather than as a crisis in public health that had some important human rights dimensions". This perception is reflected in the mountain of uninspiring social science literature on AIDS, a morass of repetitive, pious liturgies about stigma, blaming, and difference. These writings conceal a collective denial of the impact of AIDS. While all of us can learn to overcome (or at least deal with) stigma and social exclusion, few can beat the virus itself.

The stakes are high: we must take more risks. In the United States blood screening was delayed because of the implications of asking donors to identify sexual practices and drug habits; HIV testing was not added to the work-up of every newly admitted hospital patient; and neighbourhoods with a superabundance of HIV seropositivity were not targeted for intensive treatment and prevention programmes for fear of stigmatising certain postal code districts. To this day the US and other public health systems put no demands on individuals to be tested and none on those found HIV positive. The prevailing view is that to demand testing and partner notification would be to treat HIV-positive individuals like criminals, and that education is the best, indeed the only, acceptable response. However, the education approach is elitist, depends on literacy and on notions of a shared community of understanding, and assumes a setting of fully emancipated and egalitarian sexuality. The refusal to recognise that there were real "risk groups" meant that public health and educational resources were spread impossibly thinly. The US National Research Council's 1993 report *Social Impact of AIDS* indicates that the US epidemic is confined to a small number of devastated neighbourhoods, especially in Manhattan and San Francisco, where a more aggressive public health response at the very start of the epidemic might have saved countless lives.

Conclusion

At what point should the right to privacy and secrecy leave off and the assumption of larger social responsibilities begin? In trying to explain the political and medical logic underlying Cuba's AIDS programme I do not mean to suggest that the Cuban model should be imitated elsewhere. Ironically Cuba is the one country with the social infrastructure in which mass education alone might have been successful in containing AIDS. Individual liberty, privacy, free speech, and free choice are cherished values in any democratic society but they are sometimes invoked to obstruct social policies that favour universal health care, social welfare, and equal opportunity. Until all people, and women and children in particular, share equal rights in social and sexual citizenship, an AIDS programme built exclusively on individual and private rights cannot represent the needs of all groups. Gays, women, and children were especially protected by the Cuban AIDS programme. A strong and humane public health system has just as often protected the lives of socially vulnerable groups as it has violated their personal liberties.