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HIV/AIDS in the Cuban Sanatorium: The Tension between Public Health and Human Rights

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INTRODUCTION

From the onset of the HIV/AIDS crisis in 1981, questions arose about how to effectively maintain the spread of the virus. Central to these questions was the line between protecting people's individual rights and ensuring the health of the public at large. This tension between public health and human rights became no clearer than in the case study of Cuba's response to HIV/AIDS. To contain the spread of the disease, Cuba began using sanatoriums in 1986, mandatory living spaces for those who tested positive for human immunodeficiency virus (HIV). At the height of the Cuban crisis in 1992, there was at least one sanatorium in each of Cuba's fourteen provinces, although their structure and use varied over the years. The use of the sanatorium in Cuba's response to HIV was debated both within Cuba itself and in the larger international community; however, these debates were widely caught up in the politics of the Cold War and the Cuban Communist era. Intrinsic to Castro's post-revolutionary Cuba was the centrality of solidarity, namely that "solidarity represents the foundation of socialist cooperative efforts," which often sits in contrast to the individualism and competition in capitalist societies (Hansen and Groce 282). This contrast between solidarity and individualism parallels the larger structures of public health and human rights.

Previous research critically analyzing the tension between human rights and public health in the Cuban response tends to ignore the context in which the HIV/AIDS crisis occurred (Anderson 97; Parameswaran 290; Pérez-Stable 564; Smallman 37). Although many researchers name communism and the 1959 revolution, they neglect the way the revolution changed health in such a way that would make an effective HIV response possible (Parameswaran 290; Smallman 37). Specifically, these researchers gloss over the public health infrastructure that Cuba created as a response to the revolution (Parameswaran 290; Smallman 37). Although a few

discuss the changes the revolutionary government made to infrastructure (Hansen and Groce 262-3; Swanson et al. 34), Aviva Chomsky alone points out the tangible ways in which the revolutionary government solidified a commitment to health, a commitment that would prove beneficial in the creation of a strong public health infrastructure (Chomsky 333). Chomsky names three main commitments, which I will thread through the remainder of my paper. First, the government outlined that health was the responsibility of the state and approached health as a social issue, meaning that proper education, food, and employment were necessary to adequate health (333). This approach solidified a commitment to equity in service of health care. In addition, Cuba, unlike other developing countries, did not settle for the care deemed "appropriate" of developing countries, rather it built strong primary care, public health, and tertiary care systems (333). This approach followed Article 12 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR) that would provide everyone with the "'highest attainable standard of physical and mental health'" (Gostin and Lazzarini 5). Finally, in Cuba, health was deemed a national project, and popular participation in that national project was essential, namely through the development of polyclinics and family doctors throughout the country (Chomsky 333). With this in mind, I will contextualize the Cuban response to HIV within the social ramifications of the revolution, the public health infrastructure it created, and the previous and subsequent epidemics in Cuba surrounding the HIV crisis. Contextualizing the Cuban response to HIV and synthesizing the historical with the legal allows for a clearer understanding of Cuba's response, not completely marred within the politics of communism. This paper adds to and complicates former scholarship on the Cuban HIV/AIDS crisis by providing a depoliticized analysis of their HIV response through historical contextualization and a hybridized interpretative lens. In this framework, I will argue that Cuba's response to HIV was

in fact not a violation of individual human rights by refuting the common claims against those rights within three major areas: compulsory testing, discrimination against men who have sex with men, and mandatory quarantine. What then can the model of Cuba in its response to HIV and its larger revolutionary health consciousness focused in equity teach the developed world, specifically the United States, about its response to HIV/AIDS?

METHODS

My research methods for this paper relied on primary documents from Cuba's health care system and legal documents from the World Health Organization and the United Nations, specifically the Joint United Nations Programme on HIV and AIDS (UNAIDS). In addition, I relied on significant secondary sources, including books and scholarly journals that focused on the larger historical and social aspects of the Cuban response to HIV/AIDS. Many of these authors conducted direct interviews and research on the ground in Cuba in the more relaxed years of the sanatorium (Hansen and Groce 267-9; Swanson et al. 38). Much of the research also highlighted the tensions between international rights and the Cuban response, as well as the efficacy of the Cuban response (Anderson; Parameswaran). Central to this analysis is implicit theoretical framework that underlies human rights and public health. In the context of this paper, I will use the terminology men who have sex with men, which is the dominantly used terminology when discussing the HIV/AIDS epidemic.

THEORETICAL FRAMEWORK

Human rights and public health provide the theoretical frameworks upon which I build my analysis of the Cuban response to HIV/AIDS via mandatory testing, discrimination against men who have sex with men, and the sanatorium. Human rights, and by extension international human rights law, aims to "protect individuals' rights against the state's interference or neglect"

(Gostin and Lazzarini 43). The international system to protect human rights grew out of the atrocities of World War II to address violations that occurred not only internally, but also externally across borders (2). The most prominent of these bills was the Universal Declaration of Human Rights (UDHR), which was adopted in 1948 and approved by forty-eight states as an attempt to create a common standard for achieving human rights (3). The UDHR gives equal significance to civil, political, social, and cultural rights (3). All of these specific rights have important significance for HIV/AIDS, particularly in regards to adequate health care, freedom of inhumane treatment, and confidentiality (22). To more fully address civil, political, economic, social, and cultural rights, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) were developed respectively in 1966. The ICESCR provides the foundation for positive rights, which "require proactivity from the state" (5). Negative rights, in contrast, suggest, "one has a duty to refrain from doing something to another" (37). International human rights law and the UDHR in particular, deal strictly with the rights of the individual.

Public health, on the other hand, consists of the state ensuring that the entirety of a population will be healthy, which "often includes governmental intervention into individuals' lives to protect the community's health" (43). Thus, human rights and its individualistic nature and public health in its collective understanding of the common good are often at odds with one another in practice. Although it is possible to mitigate the extent to which either individual or collective well-being is infringed upon, often one takes precedence over the other. A parallel exists between the theoretical frameworks I will use and the political paradigms present in this case study. The Western hegemonic narrative, specifically the U.S., thrives off capitalism, an economic and political system that privileges the individual and avows meritocracy as the

foundation to economic prosperity. Conversely, Cuba and Castro's communism builds off an understanding of the Cuban collective, namely that equity is standard and popular participation and strong government involvement are essential to a prosperous society (Chomsky 333). Furthermore, the revolution solidified the revolutionary socialist notion of solidarity essential to Cuban civil society (Fink 715). Analyzing Cuba's reaction to the HIV/AIDS crisis through both paradigms thus enables this study's uniquely depoliticized examination of its efficacy and the potential model it offers the world for equitable public health infrastructure.

HISTORICAL BACKGROUND

Cuban History Pre-& Post-1959 Revolution

After gaining independence from Spanish colonial rule in 1898, Cuba became a protectorate of the U.S., and with the addition of the Platt Amendment to the Cuban constitution, the U.S. was granted the ability to intervene in Cuba's affairs and to send in troops at will (Smallman 36). By the 1950s, decades of economic dependency on the U.S. and its sugar market had left Cuba impoverished, leading to the rise of radical revolutionaries organized by Fidel Castro (36). In 1959, the Batista government fell and Castro came to power (36). With his rise to power came a significant amount of reform, namely around distancing Cuba from the U.S. and socializing Cuban services (36). Cuba nationalized its oil companies, to which the U.S. responded with suspending sugar imports and the eventual economic embargo that would last into the twenty-first century (36-7). Despite its relative economic isolation and the prolonged embargo, which would reach its full effect in 1991 during the Special Period, Castro's revolutionary government remained committed to the health of the population. The government approached health from an equitable standpoint, building strong primary care, public health, and tertiary care systems through polyclinics and the Family Doctor and Nurse Program (Chomsky

333). In fact, Cuba nationalized its pharmaceutical companies, eventually eliminated fees, and absorbed private health care into a national system (Smallman 38). Cuba's health care became a matter of national importance and popular participation (Chomsky 333).

Creation of Cuban Public Health Infrastructure

Central to Cuba's health care system was the training and practice of its revolutionary doctors. In the early 1960s, new positions opened for medical students at the University of Havana Medical School to participate in the Rural Health Service, an initiative by the Ministry of Health that encouraged doctors to serve in the rural mountainous regions of Cuba (Brouwer 36-7). In the 1970s, Cuba established local polyclinics, which became the model through which Cuban delivered primary care–in the form of community care. Cuba's attendance at the Alma-Ata International Conference on Primary Health Care in 1978 came to play a significant role in the further development of its health care infrastructure. At the Alma-Ata Conference the international community set an agenda to focus on a Primary Health Care (PHC) model, which centralized the principles of "human rights, social justice, and equity" (Whiteford 38). The PHC model set forth at the conference represented a radical set of principles that differed widely from existing health care models in Europe, Latin America, and the U.S. based in biomedicine and specialty care (39-40). This new PHC model prompted Cuba to follow through with its own version of primary care, namely through the Family Doctor and Nurse Program, the only national system in which the PHC model survives today (40). Throughout the 1980s, the Ministry of Public Health enabled the growth of medical school faculties in every province of Cuba (Brouwer 61). In 1984, the Ministry of Public Health also adopted the Family Doctor and Nurse Program called "*medicina general integral*, which is usually referred to as 'comprehensive general medicine'" (61). Graduates from this program formed teams of two, with one doctor and

one nurse assigned to every neighborhood in the country. *Brigadistas sanitarias* or health brigades, comprised of neighborhood residents, assisted these neighborhood teams by promoting public health campaigns, reinforcing governmental statements, and exemplifying behavioral changes (Brouwer 61;Whiteford 44). These health brigades, trained by the Cuban Ministry of Health, provided support in Cuba's polio vaccination campaign in the 1960s as well as the subsequent dengue outbreak in 1981 (Whiteford 74-6). By 2004, these teams and health brigades served around 99% of the Cuban population with each team taking care of 120-150 families in each neighborhood (61). Much of the creation of this community-based medical system continued in the revolutionary spirit of Che Guevara, an Argentine physician who became a prominent leader in the Cuban revolution (Brouwer 12). Guevara's philosophy was that the creation of a robust nation rests on the work of the social collective, centrally that of revolutionary doctors and the move towards social medicine (Guevara). This same thread of working as a collective society to form Guevara's robust nation is visible in the way Cuba has used its revolutionary health system to combat U.S. capitalism and its hegemonic domination in the Western hemisphere.

Much of the politics surrounding the development of health in Cuba are caught up in the politics of the Cold War; therefore, analysis must at all times take into consideration the "one-upmanship" that was characteristic of countries' actions at the time. By 1961, Castro had declared himself a Communist, what Smallman refers to as a declaration that could have just as much been about conviction as necessity (37). Feinsilver characterizes Castro's vying to become a "world medical power" as one he knew would win symbolic victory in Cuba's Communist competition against the United States (22). Feinsilver describes:

> The central metaphor of Cuba's anti-imperialist struggle as recounted in this analysis is that of health. The health of the individual is a metaphor for and symbol for the health of the "body politic," and in which the achievement of the status of "world medical power" is synonymous with victory over the imperialists. Medical doctors are the protagonists in this war both at home and abroad. They are warriors in the battle against disease, which is largely considered a legacy of imperialism and underdevelopment. (22)

I would counter the argument that Cuba only used health as a means and a symbol for their anti-imperialist struggle. Rather, Cuba's core socialist values and its commitment to equity were the impetus behind the public health infrastructure that was responsible for Cuba's medical achievements. However, the ties between individual health and the health of the body politic in the spirit of Che Guevara is an essential frame of reference for understanding Cuba's health infrastructure and its subsequent response to HIV/AIDS.

Dengue Fever Epidemic

In order to understand how the sanatorium followed a pattern of public health response, one needs to focus on earlier responses to epidemics in Cuba, one of which was the dengue fever epidemic. Dengue fever is a mosquito-borne virus that can develop into dengue hemorrhagic fever (DHF) or dengue shock syndrome (DSS). There are four different strains of dengue virus: dengue-1 through dengue-4, any of which can develop into DHF or DSS (Chomsky 337). Many Caribbean countries endured dengue outbreaks in the 1950s, but the first case of dengue-1 struck the island in 1977 (338). This dengue-1 outbreak did not develop into any cases of DHF or DSS; however, a dengue-2 strain that struck Cuba in 1981 that led to numerous developments of DHF and DSS, quickly reaching epidemic proportions (338). The Cuban government, and by extension the health system, mobilized to fight the dengue epidemic in two ways: through

supportive medical care and a popular sanitation campaign (338). Together, the media, schools, places of employment, neighborhoods, and organizations all over the country worked to eliminate potential breeding grounds for dengue-carrying mosquitoes as well as helping to identify people living with symptoms of dengue fever (338). Cuban doctors adopted a "'liberal hospital admission policy,'" which admitted those early on rather than when patients were already in shock, reducing the number of fatalities (338). This popular response to dengue is demonstrative of how the revolution transformed health, making it necessary that the entire country participate and respond in a time of public health crisis. In addition, the government enacted an aerial spraying of malathion covering 240,000 hectares and an education campaign to help people identify potential breeding areas for dengue (338; Feinsilver 87). Although popular participation was necessary, the malathion spray and education campaign display the way in which the state saw health as a priority. Furthermore, trained "health armies," carrying larvicide sprayers were sent out to inspect and spray every house in Cuba (Chomsky 338). This again used popular participation of the Cuban people as well as the community-based medical system already in place.

Using these three factors: popular participation, state-run health, and community-based medicine, the Cuban response to dengue fever resulted in success, eliminating the disease on the island in four months' time (338). In comparison, multiple outbreaks have occurred in Hawaii, taking 8 to 10 months to eliminate dengue in a much smaller place (Goldschmidt 2015). Of course, some argue, like Feinsilver, that contemporary rumors suggesting that the Central Intelligence Agency (CIA) intentionally introduced dengue into Cuba enabled Cuba to use its effective response as a symbol of the power struggle against U.S. imperialism (89). However, regardless of any ulterior motives, the Cuban response to dengue clearly demonstrates how the

changes prompted by the revolution around health were clearly effective in the onset of a public health crisis. In fact, although confirmation is lacking, some research suggests that the hospitals in the dengue epidemic served as models and forerunners to the HIV sanatoriums.[i] If understood within this historical context then, the response to HIV with its use of the sanatoriums does not seem exceptional, especially considering that the onset of the virus in Cuba came right off the heels of the dengue fever epidemic.

Early History of the Cuban HIV Crisis

Cuba's first reported case of HIV occurred in 1985, later than most countries, which some attribute to its geographical isolation and strict immigration policy (Anderson 96; Hansen and Groce 265; Swanson et al. 34). Soldiers, health workers, diplomats, and other officials who had been supporting military regimes abroad in Africa in countries such as Angola and Ethiopia dominated early cases of HIV in Cuba, many of which were heterosexual cases of transmission (Smallman 39). Interestingly enough, although "Africa" was to blame for the onset of the virus in Cuba, unlike its U.S. counterpart, Cuba did not spend time blaming the African continent for its epidemic (Chomsky 341). Reacting more promptly than the U.S., Cuba destroyed all imported blood in the country in 1983, even before the first reported case (Smallman 39).[ii] By 1985, the country began routine testing of HIV. Those initially tested were Cubans who had been out of the country; in 1988, this was extended to all patients admitted to a hospital and those who had contact with foreigners (40). The testing was extended even further in 1992 to cover all sexual partners of those who were HIV positive, blood donors, hospital patients, pregnant women, tourists, and merchant seamen (Chomsky 344). Although the government punished those who knowingly infected another person with HIV with imprisonment, Chomsky argues that no real

coercion was necessary to conduct testing because routine testing was common in Cuba (345-6; Smallman 53).

Meanwhile, in 1986 the first sanatorium was constructed in Los Cocos in Santiago de las Vega, a suburb of Havana, in a facility that originally had been a rest and recreational center for the military (Smallman 41). The Ministry of Defense, who administered the sanatorium until 1989, deemed this an appropriate spot because military officers made up many of the early cases (41). Those living in the sanatorium were allowed to leave the facility with a chaperone, but those who left without permission incurred a 50-peso fine (Chomsky 346). In 1989, Dr. Jorge Pérez, a specialist in HIV/AIDS care and the director of the Institute de Medicina Tropical Pedro Kouri, took over control of the sanatoriums, making significant reforms, which included tearing down the walls and barbed wire surrounding the Santiago sanatorium and integrating residents in the other sanatoriums built in neighboring provinces. (346). Other reforms included allowing residents to practice their professions inside the sanatoriums, and evaluating residents after six months to judge whether they were "fit" to leave the sanatorium (347).

The determination of who was deemed "fit" to leave the sanatorium depended on multiple factors including education and support systems. Residents deemed fit had to undergo the sanatorium's education programs and thus subsequently demonstrate understanding of this education, most specifically the "capacity and motivation to avoid high-risk sexual behavior" (Hansen and Groce 272). Other factors included the demonstration of knowledge and compliance with basic lifestyle choices surrounding HIV including diet and medications (Fink 715). Professionals also made sure that support networks surrounded patients to help them maintain healthy behavior and lifestyle choices while living outside the sanatorium (715). Most important to the health professionals was that residents continued healthy behavior and lifestyle outside of

the sanatorium in order to ensure that the virus did not spread outside the sanatorium's walls (715). In many ways, the determination of who was deemed "fit" to leave demonstrates the synthesis of the individual and the collective in the Cuban response. The health professionals in the sanatorium wanted to ensure the well-being of each of its patients; however, each individual's health needed to be ensured so that the health of the Cuban population remained steady.

By 1992, a sanatorium existed in every province in Cuba (Chomsky 346). After initial testing, counselors who were also seropositive with HIV, informed newly positive patients about their status (Parameswaran 300). One nurse and a physician also informed positive patients about their condition and the admission to the sanatorium (Swanson et al. 37). The sanatoriums consisted of residential neighborhoods with single units, duplexes, and apartments (Swanson et al. 37). Each of the sanatoriums provided free medical care, access to medications, food rations, and salaries for those not working due to living in the sanatorium (Smallman 40; Swanson et al. 38). Residents there also underwent an intense education program, entitled "Living with HIV" that focused on behavior, primarily promoting responsibility in relationships to diminish unsafe sexual contact with infected persons (Swanson et al. 37). Peer educators through *Grupo de Prevencion del SIDA*, or GPSIDA, helped facilitate this education, which covered clinical and legal information, hygiene, sexuality, and social ramifications (Hansen and Groce 270-1). Family members and friends were allowed to visit those living in the sanatoriums and patients were allowed to leave for educational events (Smallman 41). Some trusted residents obtained weekend passes and the government permitted HIV-positive couples to live together in the sanatorium if both were infected; however, officials did not allow uninfected partners or children in the sanatoriums (41). In 1993, Dr. Pérez enacted further reforms including the ability to spend

weeknights and weekends away from the facility after the six-month evaluation (Chomsky 346). This year also marked the transition from a mandatory residence program to a form of ambulatory care (347). About 75% of the people living with HIV in Havana were given the option to leave and 68% of them decided to stay, often citing that the comforts of living, the special diet, and the community outweighed what they would have received outside the sanatorium (347).[iii] As will be discussed below, the evolution of the sanatorium and the surrounding Cuban HIV/AIDS crisis coincides with the Special Period of economic crisis and the neuropathy epidemic. What the preceding discussion affirms is that Cuba's sanatoriums, particularly after Dr. Pérez's reforms, demonstrate a synergy between human rights and public health. The sanatorium protected the public at large from a widespread epidemic, while also providing individuals with adequate social amenities and care.

HUMAN RIGHTS VERSUS PUBLIC HEALTH

Compulsory Testing & Screening for HIV

According to Article 12 of the UDHR, no one should be subjected to arbitrary interference, i.e. compulsory testing and screening if it interferes with privacy, family, or home (United Nations "Universal Declaration"). From the outset, many would immediately deem Cuba's mandatory testing of individuals as interference; however, Cuba's testing practices are similar to other countries with effective testing methods (Anderson 97). At least fourteen countries including Cuba made testing mandatory for non-temporary entries ("The HIV Infection in the Health").[iv] Guideline 3b of the International Guidelines on HIV/AIDS and Human Rights states any HIV-related "public health legislation should ensure that HIV testing of individuals should only be performed with the specific informed consent of that individual" (United Nations, "International Guidelines" 27). Cuba accurately followed these guidelines through the help of

their public health infrastructure, namely their Family Doctor and Nurse Program. Family doctors conducted the majority of the HIV testing, while the polyclinics conducted the remainder of the anonymous testing (Anderson 97). These family doctors had already built a strong rapport with many of the communities where they were working, thus this testing was not "compulsory" as international critics in the media would suggest (McNeil 2012). In addition, Cuban blood tests required patient consent, which continues to be a "fundamental element of Cuban medical practice" and public health (Anderson 98). When a patient tested HIV-positive, a medical professional conducted a structured interview to determine that person's sexual contacts (98). A nurse or family doctor, again part of the Family Doctor and Nurse Program, followed up privately with these contacts for virus tracing (98). In the instance of testing, then, the revolutionary change in health, namely the creation of a holistic health infrastructure, proved beneficial. The Family Doctor and Nurse Program allowed the government to conduct testing without violating any individual rights. Because there is sufficient evidence to show that Cuba required informed consent and maintained patient privacy, the claim made by Gostin and Lazzarini that Cuba's mandatory testing policies did not comply with international human rights law is unfounded (90).

Discriminatory Practices Against Men who Have Sex with Men

Despite changes in social practices, research suggests that "machismo is alive and well" in Latin America (Smallman 5). Machismo describes the strong masculine pride characteristic in Latin America. Practices and social constructions around machismo differ by Latin American country, but there are also some common accepted social practices surrounding machismo. For example, "husbands are expected to take the dominant role within marriage" and men having sex outside of the marriage is commonly accepted (5). In contrast, women who have an affair often

lose their social status and face ridicule (5). However, there is a caveat when discussing sexual relations between males. "Men who penetrate other men" are seen as "dominant and macho" and thus "not viewed as homosexual" (123). Conversely, the male who is penetrated "is believed to lose all qualities of maleness" through this act (123). It is this specific group of men who are penetrated that are defined as homosexuals (123). This socialization around the practice of machismo must be included in the contextualization of Cuba's response, particularly its discrimination against men who have sex with men. This is not to excuse any Cuban behavior based on cultural relativism, but to emphasize that the imposition of Western notions of imperialism often constitutes a form of imperialism (Massad 41). There are essential nuances that are important in understanding the historical ways Cuba has treated men who have sex with men and the non-governmental organizing of gay-identified related groups in Cuba.

Following the revolution, Cuba adopted policies directed at men who have sex with men, many of which were supposed to "reeducate…homosexuals" (43). Cuba created Military Units to Aid Production, or UMAPs, which were essentially camps for those unfit for military service, many of which were men the government deemed too effeminate (44).[v] Forced labor was a revolutionary obligation for the majority of Cubans; however, conditions in these camps were especially terrible (44). Although Cuba phased out these UMAPs in 1969, the government continued to ban men who have sex with men and those deemed effeminate from all branches of employment where they would encounter children, and the police heavily suppressed any gay-identified organizations (44). These policies improved into the 1980s, and thus the association of the sanatoriums with discrimination against men who have sex with men is misplaced. First, men who have sex with men were never singled out in the early stages of testing for their specific sexual orientation, in part, because heterosexuals made up the majority of those infected early on

(Anderson 96). Following the development of the sanatoriums, U.S. critics suggested that Cuba was unfairly using the sanatoriums to single out men who have sex with men; however, this was again not the case (Anderson 96). Because of the previous treatment of men who have sex with men in Cuba and Cuban machismo, scholars question the prevalence of homophobia in the early days of the sanatorium (Lumsden 164). However, Scheper-Hughes contends that this homophobia can be attributed to conflicts between homophobic soldiers and men who have sex with men who lived amongst each other in the sanatorium in its early years (Chomsky 344; Farmer 71).

At the same time, the discourse surrounding non-governmental organizations in Cuba complicates the role of men who have sex with men in the sanatorium. In Cuba, mass organizations were supposed to form naturally post-revolution, fueled by popular participation (Gray 8). Traditionally, there are the "Big Seven" mass organizations in Cuba: Committees in the Defense of the Revolution (CDR), Cuban Workers Union (CTC), National Association of Small Cultivators (ANAP), Communist Youth Union (UJC), Federation of Middle Level Students (FEEM), Federation of Cuban Women (FMC), and the Federation of University Students (FEU) (Gray 8-9). The definition of mass organizations was changed during the Special Period, in 1996, when the Central Committee of Cuba's Communist Party extended their definition of civil society to include mass organizations and non-governmental organizations (11). It also recognized civil society as "'socialist' construct", revealing that "the state remains cautious about the active involvement of non-governmental actors in the country's social development" (11). As of 2005, the Ministry of Justice has 2,200 legally registered civil associations or non-governmental organizations (NGOs) in Cuba, however the Ministry does not willingly share much information on these groups (11). Most of these organizations seem to have "little

influence outside of their membership" with developmental NGOs making up around 25-50 of the total list (11). This complicated discourse in Cuba surrounding NGOs must be considered when discussing the formation and work of GPSIDA during the use of the sanatoriums.

In conjunction with Dr. Pérez's enactment of reforms, an informal group of predominately men who have sex with men organized to form the *Grupo de Prevencion del SIDA,* or GPSIDA (Hansen and Groce 266). GPSIDA consists of HIV-positive people, health professionals, and social scientists that work to support HIV-positive people and educate the community about HIV-infected people and their experiences (266). However, technically GPSIDA is the only "officially sanctioned organization of HIV-positive people," one of a small number of seemingly effective NGOs in Cuba (282; Gray 11). Some HIV-positive and at-risk gay men expressed disillusion with the fact that GPSIDA is the only organization available to support them (Hansen and Groce 282). Any effort to organize in the community among themselves was unauthorized and thus deemed illegal. (282). Because of the fact that the Cuban government had to sanction the NGO, much of its work seems tied up with the government's response to AIDS. For instance, members of GPSIDA were the peer educators that often helped facilitate conversations and education within the sanatorium (270-1). In this instance, they may be an independent organization in name, but they were also participants in the Cuban response within the sanatorium.

Although the complicated notion of NGOs in Cuba is important, debating whether NGOs were necessary to the Cuban response is outside the scope of this paper. However, the fact that popular participation by the Cuban people created GPSIDA and then the Cuban government pseudo-subsumed GPSIDA under the state follows the revolutionary logic outlined by Chomsky. The state controls health care, but because its proper distribution requires the help of all Cuban

people, to fill in the gaps where necessary, thus the role of GPSIDA peer educators fulfills revolutionary ideals that synergize individual care with equitable distribution. Cuba's response to its epidemic contrasts significantly with the highly-lauded response in Brazil. In Brazil, grassroots organizations and funding from the international community allowed NGOs to play a major role in invigorating a strong public health response from the national government (Smallman 82). Each entity (NGOs, civil society, government, and health professionals) proved necessary to create a swift and holistic response to the crisis.[vi] Despite the fact that Cuba did not follow this holistic model, its response was still effective in providing adequate and immediate care. It is also important to note that at that time, the ban on NGOs was universal, meaning no at-risk or special interest group had the ability to form an organization without government approval. This lends evidence to the argument that the Cuban government did not single out men who have sex men in regards to HIV, specifically in the sanatorium. In fact, Dr. Pérez's reforms allowed the space to create such an organization that spoke to the needs of that community. Although the government does not recognize it as a strictly gay organization, and the Cuban government has the ability to use its successes for its own advantage, the specificity of discrimination against men who have sex with men is unfounded within the sanatorium.

Mandatory Quarantine

The strict Cuban quarantine period occurred early in the response to HIV/AIDS, spanning from 1986 to 1989. The impetus for the use of sanatoriums found its roots in a 1982 Cuban law that allowed for the use of isolation for the public's health (Anderson 96). Some scholars from the human rights perspective argue that the "focus on physically separating infected and non-infected individuals is inappropriate for HIV/AIDS since the virus is not casually transmitted and generally depends on the voluntary behavior for both transmission and prevention" (Gostin and

Lazzarini 103). But, when considering the Cuban context, where non-governmental groups were illegal and forms of isolation and mandatory testing had proved effective in the past, the use of quarantine to contain the public health crisis was not a gross violation of human rights. In fact, it perfectly aligned with prior response. In addition, Cuba is a relatively small nation geographically, roughly less than the size of Pennsylvania, thus such a stringent response would contain the virus quickly. More to the fact, the sanatorium was not the place its critics described it as. I argue that the strict quarantine and the forms of quarantine that followed were not the equivalent of a prison and thus not a violation of international human rights because Cuba provided patients with necessary social services that were not available to the majority of Cubans.

Much of the U.S. rhetoric around the sanatoriums (predominantly in popular media) argues that the sanatoriums were equivalent to a prison.[vii] However, what these arguments miss is that Cuba made a distinction between those sent to the sanatorium and those sent to prison. An old Cuban public health statute prohibits the intentional infection of another with the disease, thus Cuba sent those found to intentionally infect another with HIV to prison rather than the sanatorium, signaling a clear distinction in justification and ideology (Chomsky 346). In addition, equating the prison with the sanatorium would imply that living in the sanatorium was equivalent to social death. Price draws on the work of Orlando Patterson and De Genova to formulate three qualities of imprisonment, which I will use as the basis of my argument (Price 6). The three qualities of imprisonment he uses are generalized humiliation, natal alienation, and institutional violence, which together produce social death (6). I will discuss each of these qualities in brief to articulate why the use of mandatory quarantine in the Cuban sanatorium was not the equivalent of imprisonment.

Price describes humiliation as separate from shame, namely that humiliation is "an exercise of domination" (42). For Price, humiliation in the prison is both illegal and pervasive but prison humiliation is characteristic because of the "organized, institutionalized, routine, and largely legal" ways in which it operates (42). Although stigma surrounding HIV was common, it did not constitute heightened stigma that occurred in the U.S., where specific groups – men who have sex with men, hemophiliacs, Haitians, and heroin drug users – were targeted for carrying the disease and even banned from schools (Smallman 45). While U.S. public institutions ostracized those living with HIV, including young children as in the case of Ryan White, Cuba created institutions to serve them ("A Timeline of HIV/AIDS"). In addition, isolating Cubans living with HIV from the rest of the population prevented them from enduring significant discrimination from individuals (45). Furthermore, none of the characteristic representations of this humiliation such as strip searches, or illegal sexual assault were documented as prominent in the Cuban sanatorium (Anderson 96).

Price's second condition is natal alienation, which refers to the idea in Patterson's paradigm that the slave loses the ties to blood in both ascending and descending generations in addition to "all formal, legally enforceable ties of 'blood'" (7). Price uses this same logic in analyzing the prison, namely that intrinsic to incarceration is isolation, specifically that the prisoner is isolated from the community and reciprocally those on the outside are isolated from the incarcerated (25). This applies both figuratively and literally and can be directly analyzed within the framework of the sanatorium. Initially, in the period of strict quarantine in 1986 there was only one sanatorium; however, by the height of their use in 1992 there was one in every Cuban province (Chomsky 346). At first, people living with HIV/AIDS in rural areas had to travel far, to just outside Havana for quarantine, but later on, because the sanatoriums were

centrally located in each province, people were not as geographically isolated from their communities (342). One aspect of natal alienation that is complicated in the sanatorium is that if partners are not HIV-positive, they cannot live in the sanatorium with their HIV-positive partner (Smallman 41). Furthermore, HIV-positive mothers could not bring their HIV-negative children with them to live in the sanatorium (41). This essential bond between partners and even more so between mother and child finds similarities with those incarcerated in the U.S. prison system in that both systems strip those within it of those essential bonds. Although, like the families of those incarcerated, families may have had to travel long distances to see those living in the sanatoriums, significant reforms allowed for more open visitations from family and friends (41). Furthermore, these reforms allowed those living with HIV to leave on weeknights and weekends if they passed evaluation after six months (Chomsky 346). The overarching fact, though, is that not only were families able to visit those living in the sanatoriums, but often those living with HIV had the opportunity to leave the sanatorium to visit their community as well. That important caveat, the increased freedom of mobility for those deemed "quarantine," is what makes the sanatorium not completely consumed by natal alienation.

Price states, "natal alienation and humiliation both imply violence" (20). He goes on to say that it is in the prison that "an institutionalized and state-sanctioned set of violent practices" takes place, some of which include access to inadequate health care and "exposure to premature physical death" (20). I argue that the sanatorium did not constitute the type of institutional violence to which Price is referring, namely because those living in the sanatorium often were better off in terms of social amenities than those outside of it. In addition, the sanatorium did not contain the division of power structure common in the prison system, between prisoner and prison guard, or parolee and correctional officer. Ironically, Cuba in its response to HIV/AIDS

followed Article 25 of the UHDR completely, providing everyone in the sanatorium with "food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control" (United Nations, "Universal Declaration"). Residents received appropriate food including tailored diets, comfortable living conditions, free medical care, and adequate compensation (Chomsky 347; Fink 714). In addition, since 2001, when Cuban pharmaceutical companies developed their own generic antiretroviral drugs, "every Cuban patient has been put on 1 of 4 therapeutic schemes" (Fink 715). The Cuban development of generic drugs and universal care outlined in the revolution means all patients receive access to these drugs free of cost (715). Cuba's antiretroviral development and universal access to free drugs came almost ten years after Brazil pioneered universal access to antiretrovirals for developing countries. However, Cuba's progress is still impressive considering its size in comparison to Brazil (Smallman 91).[viii] In Cuba, some residents opted to stay in the sanatoriums even after the transition to the ambulatory care centers lends even more credence to the quality of care and community within the sanatorium that was not always available on the outside (Fink 715). The social services provided the sanatorium residents, which comply with Article 25 of the UHDR and the fact that many volunteered to stay proves that the sanatoriums did not constitute the institutional violence intrinsic to a prison.

CUBAN HISTORY POST-HIV CRISIS

Special Period

After the fall of the Soviet Union in 1989, Cuba lost its main economic alliance and thus a massive economic crisis struck the island, in what came to be referred as the "special period in time of peace" (Chomsky 351). The end of the Soviet Union signaled the end of foreign trade,

namely the ability to import petroleum for industry (351). Sugar production collapsed, factories shut down, electricity became almost obsolete, and cars and buses disappeared (351). In particular, the strong ties to the Soviet Union had mitigated much of the impact of the U.S. economic blockade, but with the collapse of the Soviets, Cuba felt the full effects of the blockade (351). Furthermore, in 1992, the U.S. extended the economic embargo to include food and medicine, which significantly affected the Cuban health system (351). Painkillers were scarce, and many doctors began to rely more on herbal medicine (Smallman 47). There was such an extreme shortage of paper that "nearly all medical and nursing journals ceased publication in 1992" (47). In 1996, the U.S. furthered restrictions by passing the Helms-Burton Act, which brought any foreign companies to U.S. court if they did business with Cuba, particularly applying to property formerly owned by U.S. citizens and Cubans who have since become U.S. citizens (48). These further restrictions made Cuba unable to obtain medicines, pharmaceuticals, and essential technological parts needed for diagnostic testing (Chomsky 352). Because of the Cuban economic and social system already in place, namely, one built on equity, Cuba was able to equitably distribute the impact of the economic crisis across society (352). In contrast to the United States, where there is a disproportionate amount of people living in poverty who are doubly affected by economic loss, in Cuba no one group felt a disproportionate affect from the economic crisis. In the hardest period before the recovery, between 1993 and 1994, hunger was the norm across Cuban society. Instead of malnutrition directly hitting the children and the poor, weight loss and malnutrition hit the adult population most prominently (352). In spite of efforts to protect the most vulnerable, due to the combination of these factors, infectious disease and parasites rose. Morbidity also rose due to issues with public sanitation (352). Yet, despite this

significant economic crisis and its lasting detrimental effects, Cuban public health indicators still remained low by international standards (353).

Although Smallman claims that the Special Period was responsible for the decline of the sanatoriums, there is evidence to refute that claim (48-9). Dr. Pérez, the doctor in charge of the Cuban sanatoriums, conducted the initial easing of restrictions in the early 1990s, allowing some residents to return home on the weekends or even full time (Fink 715). Dr. Pérez and his colleagues used the outcomes from these residents as pilot studies to prove that patients were not spreading HIV to their family and friends upon returning home (715). Dr. Pérez brought these findings to the government, "arguing that HIV is a chronic infection and that most patients, if given education, will not transmit it to others" (715). As a result, he convinced the government to move towards a more ambulatory care system in the sanatorium, and long-term confinement ended in 1994. The transition to ambulatory care facilities and the lessening of restrictions in the sanatorium were not purely economic, but rather based on the changing nature of the epidemic and the needs of the Cuban people.

The Special Period also brought about a slow economic opening in Cuba with foreign investment and tourism as well as the legalizing of the dollar in 1993 (Chomsky 352). In 1994, "free" farmers markets, whose prices were governed by supply and demand opened in Cuba (352). Although deemed as still having strict limits within the market, some argue that this economic opening brought the beginnings of inequality to Cuban society (352). For instance, those Cubans who have access to dollars were able to have access to food, goods, and entertainment that other Cubans did not (352). Although these concerns of inequality are valid, what is remarkable about the Special Period in Cuba is that the strength of the health system prevailed. The Family Doctor and Nurse Program allowed the Cuban people to continue

receiving care in a free setting. Furthermore, for many years, Cuba had been at the forefront of creating medical technology, and this continued even in the Special Period. Cuba was able to produce pharmaceuticals for export and continue their medical tourism, which brings low cost services to foreigners (354-5). This strongly suggests that the transition from the long-term confinement was again, not economic, not based on sacrificing people living with HIV to save money, but on once again returning to the same synergy of public health and human rights explained in relation to dengue fever above and explained in relation to dengue neuropathy below. In responding to the needs of the changing epidemic and its people, Cuba allowed individuals to attain greater freedom with fewer restrictions while simultaneously maintaining the health of the Cuban population at large. The lessons Cuba learned from its rapid response to the HIV/AIDS crisis, particularly during the Special Period proved useful in the neuropathy epidemic that followed.

Neuropathy Epidemic

In 1991, an epidemic of optic and peripheral neuropathy struck Cuba, which affected about 51,000 people by the beginning of 1994 (348). The Special Period brought about by the end of the Soviet Union and the increased economic embargo with the U.S. contributed to the onset of the epidemic, which stemmed from nutritional causes (349). Despite the fact that the U.S. embargo played a direct role in the nutritional deficiencies and by extension the neuropathy epidemic, the U.S. was silent on the epidemic, especially considering the fact that neuropathy infected more people than HIV (348-50). Unlike other countries, Cuba responded to the economic crisis by increasing their protection of vulnerable populations, particularly children, pregnant women, and the elderly (349). By 1993, there were 3,000 to 4,000 cases occurring per week, and thus the Cuban government launched an effort to test, study, and treat the disease,

with the help of their already foundational public health infrastructure (349). The Civil Defense for Disaster Relief, the Ministry of Public Health, and the Cuban Academy of Sciences formed a task force for research and testing of neuropathy (349). Simultaneously the government mobilized the family doctors. Where the onset of the epidemic occurred, in Pinar del Río, health officials recognized that Vitamin B deficiency seemed to be a risk factor for neuropathy (349). Thus, the government began manufacturing vitamins, which the family doctors distributed to every citizen in the region and eventually the rest of the country (349). This continued on a monthly basis through the late 1990s (349). By the end of 1993, the neuropathy epidemic was over (349). In the end, Cuban women were more affected by the epidemic than men; however, the government provided extra food rations and nutritional supplements to pregnant women, children, and the elderly, which meant that these subgroups were rarely among those affected (349). Contextualizing the HIV/AIDS epidemic within the dengue fever epidemic and neuropathy epidemic makes clear how the response to HIV/AIDS was just one part of an effective public health response by the government's health infrastructure and the popular participation of its people. Cuba's ability to synthesize both human rights and public health clearly sets its socialist health system apart from the rest of the world.

CONCLUSION

Present Day

This revolutionary legacy in public health continues into the present day. Currently, Cuba is the first country in the world to receive validation from the World Health Organization that it has eliminated mother to child transmission of HIV (UNAIDS, "Cuba Ensures"). In addition, it has continued its leadership among other nations, deploying their international medical brigades in places like Haiti and Bolivia and collaborating with such countries to continue training of

medical professionals in a community-based manner (Brouwer 12). Furthermore, Cuba continues to stand at the forefront in development of medical technology and pharmaceuticals, including working to develop an HIV vaccine (Fink 714). UNAIDS's estimates for deaths due to AIDS in 2015 was at less than 500, with the prevalence rate from ages 15 to 49 at 0.3%, compared to a global prevalence rate of 0.8% (UNAIDS "Cuba"). Because economic reforms in the Special Period brought about levels of inequality in Cuba, many question what effect the end of the U.S. economic embargo will have on health (Cuellar 217). However, what remains true is that Cuba's commitment to health equity and attention to its vulnerable populations has proved effective in developing an equitable response in times of public health crisis. The development of solid public health infrastructure, through multiple levels of facilities, the Family Doctor and Nurse Program, and popular participation by the Cuban people within organizations and without, have sustained Cuba through multiple health epidemics. This attention to the individual, but also more importantly the bridges of solidarity between the people and its government have worked to ensure both human rights and public health.

When comparing the Cuban HIV/AIDS crisis to the U.S.'s response in particular, the commitment to health equity is what seems to set Cuba apart. In comparing the two cases, former Cuban Vice Minister of Public Health, Terry Molinert, clearly explains:

> In Cuba, nobody lacks economic resources because of being an AIDS carrier. In Cuba, no one dies abandoned on the streets for lack of access to a hospital. In Cuba, we haven't had to open hospices so that patients who have been abandoned have a place to die in peace. In Cuba, no one's house has been set on fire because its inhabitants are people with AIDS. In Cuba, no homosexual has been persecuted because he's assumed to be

> likely to spread the virus. In Cuba, we don't have the problem of national minorities of drug addicts with high rates of AIDS. (qtd. in Farmer 73)

It is in this spirit of equity, the spirit first outlined by Cuban revolutionary Che Guevara that Cuban health care lives on. By providing a contextualized and depoliticized analysis of the Cuban HIV/AIDS crisis, highlighting compulsory testing, discrimination against men who have sex with men, and the sanatorium, I have proven that the Cuban response to HIV/AIDS was not a violation of individual human rights. Thus, the Cuban response presents the potentiality for a synergy between individual rights and public health when a society builds a public health infrastructure founded in equity and carries on in the spirit of revolutionary socialist solidarity.

Notes

[i] See Anderson 96.

[ii] The U.S. remained hesitant to apply strict regulations for blood transfusion and blood products until around 1984, three years after the first reported case of HIV in the U.S. In particular, this had detrimental effects for the hemophiliac population, half of which became infected with HIV after using blood products that were contaminated ("HIV/AIDS").

[iii] Some of the data and details coming from the Havana sanatorium are not completely representative of sanatoriums in other provinces because of its location just outside Havana, its size, and the fact that it was open to foreign visitors (Smallman 40).

[iv] Other countries included the Soviet Union, South Korea, Bolivia, Peru, and Iraq. See World Health Organization, *Directory of Legal;* "The HIV Infection in the Health"; Raeburn 5B

[v] In comparison, the United States military banned gays, lesbians, bisexuals from serving openly in the military under "Don't Ask, Don't Tell" from 1994 until 2001 (Bumiller).

[vi] See Smallman 67-112.

[vii] See Anderson for more explanation. See also Zonana.

[viii] See Smallman Ch. 2 for more info on Brazil as the gold standard for universal access to antiretrovirals.

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My research strategy for this paper relied on primary documents from Cuba's health care system and legal documents from the World Health Organization and the United Nations. In addition, I relied on significant secondary sources, including books and scholarly journals that focused on the larger historical and social aspects of the Cuban response to HIV/AIDS. Many of these authors conducted direct interviews and research on the ground in Cuba in the more relaxed years of the sanatorium. Many of these secondary sources came directly from Goucher Library's database as well a variety of books through interlibrary loan. I relied on a few of the books from the interlibrary loan for their significant theoretical framework throughout the entirety of the paper. I also utilized Goucher's extensive online international newspaper database to look at global perceptions of the Cuban sanatoriums, which were useful in highlighting the difference between valid arguments and sensationalism. Conducting research for such a large paper is difficult, especially when it requires so much reading from so many different kinds of sources. Through this experience, I came to rely on a technique taught to me my Professor Bess, which is to put sticky notes on important information as I read, using different colors depending on where I would be using each source in the paper. This allowed me to keep my thoughts and sources organized and ensured the writing process went more smoothly. It is a research and writing technique that I have carried over to all my other work, especially as I embark on my senior thesis.