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Evolution and Ethical Aspects about HIV/AIDS in Cuba

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Abstract

The Human Immunodeficiency Virus (HIV) is primarily transmitted through sexual contact, an essential activity for human reproduction, and is accompanied by behaviors and actions that facilitate its acquisition. Objective: To examine some ethical conflicts related to HIV/AIDS from the beginning of the epidemic to the current scenario in Cuba. Methodology: Five important scientific documents were reviewed to sustain the authors' perspective on the link between ethics and HIV/AIDS. Results: Evidence was obtained about the satisfactory evolution of the disease in the country, the presence of ethical conflicts when applying epidemiological control measures, and projections for their elimination. Conclusions: The positive results achieved in controlling the HIV/AIDS epidemic in Cuba should not obscure the ethical conflicts arising from the epidemiological control activities implemented since its very beginning, nor the ethical dilemmas faced by people living with HIV/AIDS.

Key Words: HIV/AIDS, epidemiological control, ethical conflict, discrimination, health behavior

Introduction

Communicable diseases have always caused alarm in the population, especially when accompanied by high mortality rates, as recently occurred with the COVID-19 pandemic. Subsequently, in the face of the endemic nature of the event, fear diminishes and a seemingly normal epidemiological situation returns. This is what is currently happening with the disease caused by the Human Immunodeficiency Virus (HIV), whose main mode of transmission is completely linked to the sexual behavior, an essential activity for human reproduction, which is accompanied by behaviors that facilitate the transmission of HIV/AIDS. A unique feature of the disease is that it has given rise to ethical conflicts that harm patients and call into question epidemiological strategies for its control. As happened in Cuba at the beginning of the epidemic, these conflicts were subjected to criticism and questioning without offering convincing evidence or arguments to support them. In this sense, the objective of this paper is to examine some ethical conflicts related to HIV/AIDS from the beginning of the epidemic to the current scenario in Cuba.

Materials and Methods

The authors' perspective on the topic was supported on five scientific documents: a) the printed testimony of the senior official responsible for HIV/AIDS control from the beginning in Cuba [1]; b) the book "HIV/AIDS Epidemic in Cuba: 30 Years of Experience," published by three Cuban epidemiologists in 2016 [2]; c) the book "AIDS: Confessions to a Doctor," published in 2007 by one of the most featured cuban experts in the care of HIV/AIDS patients [3]; d) the results of two Master's theses in Bioethics in Cuba conducted in 2015 [4] and 2023 [5]).

Development

a) Ethical conflicts at the beginning of the epidemic.

As is well known, the alarming situation caused by the laboratory diagnosis of HIV in the United States in 1981, with the resulting new disease called Human Immunodeficiency Syndrome (AIDS), led to a global political and scientific mobilization to address the epidemiological challenge posed by this health event.

In August 1983, a meeting was called by the Pan American Health Organization (PAHO) to analyze the problem of AIDS in the Americas. A National Commission to Prevent and Combat AIDS was immediately created. In 1986, the first two cases of AIDS in Cuba were diagnosed at the Pedro Kourí Institute of Tropical Medicine (one a Cuban technician who had returned from Mozambique and his partner), in addition to four Cubans in the same country, with the same source of infection: a native woman.

At that time, it was decided to admit all diagnosed patients, following an individual interview with expert psychologists who also interwied their families to obtain their consent before admission. The admission objectives were:

- To provide the best medical and social care to HIV patients and carriers.
- To prevent sexual transmission due to irresponsible behavior by both patients and carriers.

The most bitter criticisms were directed at the decision to require mandatory hospitalization of patients and the mass implementation of serological tests to detect them. All accusations were clarified before several international experts in a panel discussion at Harvard University in 1992 entitled "International AIDS Policies: The Case of Cuba." [1]

This would be one of the first, if not the first, of the ethical conflicts arising from AIDS in Cuba, when two of the main national control measures were called into question, which definitively contributed to the absence of transmission of the disease in the country for many months. These measures had legal force endorsed by Decree Law No. 54 of 1982 and the Health Law of 1983. In 1991, the National AIDS Prevention and Control Program was implemented, and in 1993, the Outpatient Care System (SAS) for HIV-positive Cubans was established.

b) Ethical conflicts in the evolution of the HIV/AIDS epidemic

According to WHO estimates for 2021, 60% of new HIV/AIDS infections in Latin America and 44% in the Caribbean were distributed among three key population groups: men who have sex with men, transgender women, and sex workers. [6] In Cuba, the HIV epidemic in the period 1986-2021 was considered low in the general population and slow-growing in urban areas; sexual transmission of the disease predominated (99.6%), and males were more affected, especially in the key group of men who have sex with men (MSM), who represented 87.4% of cases and 70% of the total diagnosed cases. Pregnant women maintained very low prevalence rates.

A decrease in the incidence rate was observed from 0.16x 1000 inhabitants in 2010 to 0.13x 1000 inhabitants in 2020. The prevalence rate was 0.4% in the population aged 15 to 49 years, and has remained stable since 2019. The most affected provinces of the 15 existing in the country, two correspond to the western region; four to the central region and two to the eastern region. [2]

In 2023, 319 cases of AIDS were reported for an incidence rate of 31.1 x 1,000,000 cases. Of the total diagnosed, 262 men (82.1%) and 67 women (21.0%). Besides, 26.7% of the total are over 50 years old. [7] It is noteworthy that in a recent study, focused on gender, the finding of mortality from HIV / AIDS in non-white women and those over 60 years of age, in particular those over 70, was interesting [8], which is possibly related to the effectiveness and efficiency of antiretroviral treatment, since "the island has 93.5 percent of people living with HIV under treatment with antiretrovirals, more than proposed by UNAIDS in its Plan 90 x 90 x 90. [9] Currently, HIV infection in Cuba has evolved to chronicity with the advent of antiretroviral drugs, which, together with the elimination of vertical transmission of the disease, raises the expectations of eliminating the infection by 2030.

On the other hand, it is recognized that HIV/AIDS is concentrated in key populations, and that reducing this vulnerability, resulting from social exclusion, is a necessary element. Several effective strategies for HIV prevention have been identified and tested, and the need to focus actions on these key populations, particularly MSM and transgender populations, has been recognized. In addition to a comprehensive medium-term strategy for the prevention and control of the epidemic, a reduction in stigma and discrimination is required.

The Global Health Sector Strategy on HIV on the accelerated path to ending AIDS by 2030 promoted a people-centered approach, based on the principles of human rights and health equity. In recent scenarios, the organization itself has directed interventions to change behaviors and address stigma, discrimination, and other structural barriers [6].

Cuba's prevention strategy is characterized by a set of public policies that center human dignity, multiple approaches integrated into prevention, broad coverage of care, treatment, and support based on primary health care, and intersectoral and community participation. However, it has not been free of barriers, including cultural taboos and available resources. It is distinguished by three fundamental elements: experiential contextual, normative ethical, and instrumental cognitive.

Regarding the normative ethical element, which is most relevant to the topic under discussion, the strategy has a conception of social justice, with evidence in the public policies that have guided actions. Some of these have been prepared in print, while others have been implicit in the measures taken by the revolution, although often not stated as such. Examples of this are the research and actions deployed on aspects of stigma and discrimination toward key populations and the establishment of a legal framework. [10]

c) Ethical Conflicts in People with HIV/AIDS

Once the situation has been summarized the HIV/AIDS situation as a health problem, it is time to observe what has happened to infected people after several years of the epidemic. One of the two studies selected as evidence aimed to identify the ethical and moral behavior of People with HIV/AIDS (PLHIV), recognizing that the disease is a complex health problem, not only because of its psycho-biological impact but also because it directly influences the individual's "moral" and "social" dimension.[4] Stigma and discrimination remain the negative impacts that accompany infection and disease, which now affect everyone, including health professionals.

The key element of this research was the development of a Moral Behavior Pattern comprised of dimensions: ethical and moral knowledge about the disease (including the social and individual

perception of the disease and the right to confidentiality); the personal meaning that HIV/AIDS has on their lives; moral relationships; moral attitude of PLHIV and attitude toward illness; individual responsibility; social responsibility; and joint responsibility.

Forty of the 45 selected individuals were interviewed, all residing in a Havana municipality. The pattern was unsatisfactory for 42.5% of PLHIV, reflecting the persistence of ethical conflicts among these individuals and their relationship with health services. For example,

• Workers or job applicants should not be discriminated against or stigmatized based on their actual or perceived HIV status, or their membership in population groups supposedly at greater risk of infection or more vulnerable to it.

• It is recognized that "stigma and discrimination persist in many health centers, where people living with HIV suffer prejudiced attitudes from providers and are denied services."

• The allocation and control of diets by the family doctor caused discomfort for PLHIV, who did not wish to be known in their area of residence.

• Diet number, antiretroviral treatment, and location of consultations are elements that identify PLHIV in the community, in addition to the indiscretions of some people who provide these services.

The second most recent study [5] included the novelty of focusing on the Bioethics of Intervention, to explore dimensions linked to the social context of chronically HIV-positive individuals attending a routine consultation at a tertiary care hospital in the country's capital. 85 individuals were surveyed, and among the vulnerabilities identified were income inequality, limited support networks, and internalized stigma.

A key and necessary element in the contextual analysis of HIV/AIDS chronicity is stigma, since the transition to chronicity entails new biomedical, but also bioethical and biopolitical challenges. The mechanisms and sources that generate it have changed since the beginning of the pandemic, but it remains key to achieving disease control and preserving the rights of infected individuals. Confidentiality about diagnosis, choice of place for health care and collection of Highly Effective Antiretroviral Therapy (HAART), among others, are some of the ways in which stigma can manifest itself, triggering isolation and uncertainty in these individuals.

As evidenced in the previous research, confidentiality once again contributes to the emergence of ethical conflicts or dilemmas. Confidentiality and trust cannot contribute to the rise of stigma and discrimination. Discrimination, as the author rightly acknowledges, increases feelings of loneliness, isolation, and self-exclusion, which can lead to internalized self-stigma. Furthermore, and no less importantly, it can lead to a decreased capacity to respond to the challenge of stopping the spread of HIV.

Discussion

The evolution of HIV/AIDS in Cuba has shown satisfactory results, and an acceptable level of endemicity has been reached, with a view to its elimination, as demanded by international organizations, as well as the obligation to maintain the health of the Cuban population. Certainly, at the beginning of the epidemic, an ethical conflict arose, regardless of the reasons for admitting patients and screening the population. The question remains: Was the massive screening and mandatory admission of patients a violation of human rights (an unethical action)? These necessary epidemiological control measures were soon eliminated, but as time passes, the question always remains as an exercise of judgment. The endemic nature of the disease, although at far from alarming rates, requires an effective and efficient strategy for its control. Priority is given, among other actions, to breaking down cultural taboos and material barriers (resources) that will, on the one hand, reduce the stigma and discrimination felt by patients and, on the other, ensure the quality of care they deserve.

In this sense, people living in low- and middle-income countries have limited access to primary and specialized health care services, and therefore do not benefit from programs aimed at the early detection of diseases. [11], such as HIV/AIDS. In Cuba, although there is a universal and free health system, various sources and actors identify problems of access to services that must be made visible and taken into account from the academic and political dimension [12]. This situation is also reproduced in other countries, although the reasons for the difficulty of access are different. For example, in Mexico, although the availability of medical services is considered a fact, that these are acceptable and meet established quality levels, there is inequity in the use, distribution and accessibility of resources. [13]

This difficulty in access, of course, significantly impacts the care that HIV/AIDS patients should receive. In Cuba, access is not critical because of the endemicity of the disease. However, it does require epidemiological action adapted to the new circumstances, given the growing population of people aged 50 and over who are at risk of becoming ill or diagnosed as chronically ill. [14] [15] [16]

On the other hand, if the cultural taboo is recognized as a barrier to developing a national control strategy, interdisciplinary and intersectoral action is essential if we intend to modify the behaviors of discrimination and rejection coming from a large portion of the population and, above all, from the health personnel who care for them, as evidenced in the results of the two choosed studies [4] [5]

At this time, the chronicity of the disease [17] requires readjusting the care processes for people living with HIV/AIDS and, in particular, observing the behavior of those belonging to the groups considered most vulnerable. Furthermore, it is essential to accept that HIV-positive people have rights, and we must ensure that ethical conflicts do not arise, as occurred at the beginning of the epidemic control.

Conclusions

It is known that HIV/AIDS is a disease that directly affects an individual's moral and social sphere, fostering feelings of alienation and marginalization in the face of intolerant and discriminatory attitudes.

The positive results achieved in controlling the HIV/AIDS epidemic in Cuba should not ignore the ethical conflicts arising from the epidemiological control activities implemented since its inception, nor the ethical dilemmas faced by people living with HIV/AIDS.

After more than 40 years since the start of the HIV/AIDS epidemic in Cuba, a qualitative change in the way we address the ethical and moral complexity of the disease is essential, even more so now that it has been recognized as a chronic illness.

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