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Indigenous peoples, HIV and public policy in Latin America: an exploration of the current situations of epidemiological prevalence, prevention, care and timely treatment

Pueblos indígenas, VIH y políticas públicas en Latinoamérica: una exploración en el panorama actual de la prevalencia epidemiológica, la prevención, la atención y el seguimiento oportuno

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ABSTRACT This article aims to describe and analyze the situations of epidemiological prevalence, prevention, care and treatment of HIV in indigenous populations of Latin America. In order to do so, 304 published materials – including declarations, public policy and health program protocols, case studies and literature reviews with local, national and regional scopes – were identified, classified and analyzed. The differential social vulnerability to HIV infection and the inequity in health care access among indigenous populations can be attributed to the juxtaposition of factors such as structural violence, gender, racism, and discrimination due health condition (living with HIV) as well as the subordinated position of indigenous peoples in societies stratified not only socially and economically but also ethnically and culturally. The few studies done in the region on epidemiological prevalence, morbidity and mortality that are disaggregated by ethnicity reveal alarming data highlighting the need for further information on the epidemic in this population so as to address its repercussions in terms of prevention, care and timely follow-up.

KEY WORDS Medical Anthropology; HIV; Indigenous Population; Racism; Public Policies.

RESUMEN Este artículo describe y analiza la situación epidemiológica, de prevención, atención y tratamiento del VIH para pueblos indígenas en Latinoamérica. Se identificaron, clasificaron y analizaron 304 materiales publicados, entre ellos, declaraciones, protocolos de políticas públicas y programas en salud, estudios de caso y revisiones del estado del arte locales, nacionales y regionales. La vulnerabilidad social diferencial en la adquisición del VIH y la inequidad en el acceso a la atención de la población indígena en Latinoamérica, con respecto a otras, se debe a la yuxtaposición de factores como la violencia estructural, el género, el racismo, la discriminación por la condición de salud en el caso de las personas que viven con VIH y la posición subordinada que, en general, ocupan en sociedades estratificadas en función de esquemas sociales y económicos pero también étnicos y culturales. Los escasos estudios desagregados por etnicidad sobre prevalencia epidemiológica y morbimortalidad existentes revelan datos desalentadores y alertan sobre la necesidad de conocer el comportamiento de la epidemia en esta población y abordar sus repercusiones en términos preventivos, de atención y seguimiento oportuno.

PALABRAS CLAVES Antropología Médica; VIH; Poblaciones Indígenas; Racismo; Políticas Públicas.

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INTRODUCTION

In 2015, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the International Secretariat of Indigenous Peoples on HIV/AIDS, Sexuality and Human Rights (SIPIA) [*Secretariado Internacional de Pueblos Indígenas frente al VIH/sida, la Sexualidad y los Derechos Humanos*], an organization that has been fighting untiringly to place the issue on the local and international agenda, launched a call to draft a Regional report on the current status of HIV in indigenous peoples in Latin America.

With the aim of analyzing the policies, declarations, programs and protocols published in connection with the access to HIV-related services, prevention, health care and treatment for indigenous peoples in Latin America, as well as providing advice on this respect in the field of public policies, research and professional practices of government agents, health sector, civil society, and among indigenous leaders and communities, the following objectives were proposed a) to map and describe the sociocultural determinants of the HIV epidemic in indigenous peoples in Latin America b) to document the access of indigenous peoples in Latin America to health care services in the area of HIV prevention, its timely detection and connection with the medical sector to receive the antiretroviral therapy and follow-up; and c) describe the main recommendations, related to the subjects under study, which were obtained from the analyzed documents, discuss their content and propose recommendations on public policies, inequity gaps, good prevention practices and health care related to HIV/AIDS, and the possibility of joint work among the indigenous communities, civil society and government sectors, from a gender and Human Rights perspective.

This is the first research study about HIV and its relationship with structural elements that affect morbidity and mortality such as underdevelopment, migration, racism, gender, sex work, social stratification, inequity in the access to health services, in particular to antiretroviral therapy and adherence, from its articulation with the differential vulnerability to the epidemic affecting the indigenous peoples of the American continent. In that sense, this is not the first epidemic in the American continent that differentially affects the indigenous population compared to the non-indigenous population, which, in the case of HIV, has a more specific impact on the ethnic-racial minorities of countries such as the United States.(1) In the particular case of Latin America, the impact of the epidemic on these populations is not known due to the lack of epidemiological data disaggregated by ethnicity.

Based on all the findings of the above-mentioned research study, this article includes a description and analysis of the experiences and documentation referring to HIV prevalence, incidence, prevention and health care in indigenous populations of the following Latin American countries: Argentina, Bolivia, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Paraguay, Peru and Venezuela. Its theoretical and conceptual framework addresses social vulnerability,(2) the political economy of HIV,(3,4) and the social determinants of health.(5).

MATERIALS AND METHODS

A review and an analysis of a total of 304 published documents about HIV and indigenous peoples in Latin America were performed, most of them drafted by research centers, universities, experts, civil society bodies, researchers, indigenous communities and international organizations such as UNAIDS, Pan American Health Organization, World Bank, World Health Organization, SIPIA, among others. In turn, another 100 materials of different types were reviewed and ruled out for not providing specific content related to HIV and the indigenous communities in Latin America, or any other epidemiological or sociocultural data on the issue under study, or complementary elements to the included information.

The search was carried out principally through significant social actors, who were well-acquainted with the subject matter, referenced by SIPIA and UNAIDS, and with access to the databases containing all the documents. We also sought for other sources of information, such as conferences programs or bibliographic references that acknowledged the existence of such documents, and in a complementary manner, we searched for other scientific documents on HIV matters in indigenous communities in Latin America, in the bibliographic databases in English and Spanish of Scielo, Scopus and Google Scholar.

The time spent in the search of these materials, which was defined during the consultancy stage, was 4 months (from October 2015 to January 2016). The short estimated time assigned to this work and the difficulty in finding documents that were scattered and fragmented was indeed a challenge in terms of the search and systematization. Moreover, the research experience of the interdisciplinary team on this health problem within the indigenous population from different countries of Latin America was another element that enriched the analysis of the gathered documents.

Based on this process of search, collection, reading and analysis of the documents, the team proceeded to classify them. The first step consisted in detecting those documents that strictly addressed the HIV problem in the indigenous peoples from those focused on other social groups or that did not provide any empirical data. Afterwards, the material was organized by country and, within each country, by fields of prevention, prevalence, incidence and medical care. Subsequently, all the documents were organized hierarchically taking into account their ability to provide scientific evidence to the study contexts, which helped to implement a method of triangulation and contrast of the sources of information to determine the scientific nature of their data. Lastly, a transversal analysis of the experiences was performed based on the proposed analytical axes. Among the compiled and analyzed documents, there was not enough material to carry out the research study in Uruguay.

Throughout the research study, the team worked jointly with SIPIA and UNAIDS through an ongoing, permanent and inclusive dialogue whose objective at all times was to receive feedback from both groups in connection to the research study.

The research study gave rise to a report of around 300 pages, including the pertinent executive summary comprising the background and the original source of this article.

RESEARCH STUDY ON HIV AND INDIGENOUS PEOPLES

In Latin America, the migratory phenomenon, poverty and gender inequality were studied as social vulnerability factors for HIV infection; this has not occurred with ethnicity and much less in its relationship with sexuality or loving-sexual diversity. Only in rare exceptions, and by analyzing records that were taken mostly by the civil society,(6,7,8) we were unable to find any information or figures related to the impact of HIV on the indigenous peoples of the region. Based on all the documents analyzed and on our own research experience in Latin America, a normalization of this situation was noted by the different social actors in charge of decision-making and health care, under the assumption of a low prevalence based on various stereotypes related to the indigenous community. We consider that, if in most Latin American countries there are no epidemiological data collection mechanisms disaggregated by ethnicity(9) or, if in fact there are, they are not effectively implemented, this is due to the political objective of exerting discrimination from the State.(10)

The problem of invisibility of the indigenous population with regard to HIV is related to several factors: 1) not thinking about the indigenous population when discussing health issues; 2) social stereotypes about who they are and how they live, as they are still considered to be exotic beings living in inaccessible places, HIV would not represent a threat to them; 3) the belief in the "natural sexuality" of the indigenous people, which claims that all of them are heterosexual and the constant association of the epidemic with homosexuality, leading to the belief that, if there are no homosexuals within the community, then there is no risk of HIV infection; 4) considering that all research studies and programs for migrants or the rural community also include the indigenous peoples; however, this is not entirely true, as no policies are being implemented taking into consideration their sociocultural specificity in a national context characterized by racist and discriminatory practices.(11)

The result is a great lack of awareness regarding the behavior of the epidemic in the indigenous peoples and, consequently, a lack of particular prevention and health care measures, which explains the growing impact, in the registered cases, in terms of morbidity due to new infections and on life expectancy for those suffering from HIV who cannot have access to the treatment, as well as a lack of public policies for this particular sector of the population.(6,12)

It is important to mention that the particular vulnerability of the indigenous peoples is not limited to simply not receiving the institutional announcements in their native language. In addition, as Núñez Noriega and Ponce(11) state:

> ...the ethnic condition is also a vulnerability factor as it implies being placed in various structures: 1) of economic exploitation that perpetuates their poverty and force them to migrate, 2) of social segregation or marginalization such as adequate health and educational systems, 3) of political and cultural subordination that hinder the full exercise of their human and collective rights as communities, and 4) of symbolic domination (racist, homophobic, class-based) which, through daily discrimination acts, shape their family, social, emotional, affective and sexual dynamics.

All these structural conditions together complicate or deprive them of the possibility of having access to an adequate sexual health status, which makes it harder for them to prevent HIV infections. Ethnicity also determines an additional vulnerability in men who have sex with other men, not only for being a population with high prevalence, but also because the forms of discrimination, stigma and racism in migratory contexts condition risky sexual behaviors.(13)

Knowing and starting to name these realities will help develop prevention and health care strategies. Silencing or concealing them under the prejudice that "among the indigenous peoples there are no such practices" or under the argument that "this topic is not to be discussed" so as not to cause greater stigma towards these communities, or to preserve at all costs the uses and customs without questioning their impact only condemns a lot of people to a situation of vulnerability towards HIV, which is added to the lack of access to quality public health and educational services for prevention and health care, as well as to fair economic conditions that would allow them to live without food insecurity, the denial of their language and culture, poverty and racism.(11)

The results of this research study and of our own research experience, in various contexts of Latin America in relation to HIV prevention/care control in the indigenous population, show that this population is in a situation of high vulnerability towards HIV compared to the rest of the population. This does not only make these peoples differentially susceptible to such infection due to unequal prevention, but also to the intermediate determinants that make it difficult for them to access health care, a timely follow-up and control, leading to catastrophic results in terms of morbidity and mortality rates, which, still in a specific yet insufficient manner, are beginning to acquire visibility.

Epidemiological situation

In a large part of Latin America, there are no ethnic data in the epidemiological records; however, over the last years, it has become common to hear researchers and activists claiming that HIV has silently entered the core of this sector of the population. With the exception of Argentina, Bolivia, Costa Rica and El Salvador, where we have not found any records of prevalence or incidence, several studies(14,15,16) highlight that, within some indigenous communities of Honduras and Panama, the prevalence is six times higher than in the general population. Furthermore, they warn that the epidemic has notably increased in the native communities of Guatemala, Honduras, Colombia, Venezuela, Chile, Panama, Mexico, Ecuador, Peru, Bolivia, and the different border areas of Brazil.

A few particular research studies have shown evidence of alarming prevalence and mortality situations caused by HIV in the following cases: the Aymara community in Chile; the Warao community in Venezuela; the Kuna and Bugle communities in Panama; and the Shuar nationality in Ecuador.

In the case of Chile, according to the estimates presented to the Ministry of Health by the anthropologist Malva Marina Pedrero, "the indigenous Aymara community of Chile, in 2010 and 2011, showed an HIV mortality rate of 9.1 per 100 thousand inhabitants," while in the non-indigenous population, it was of 2.9 per 100 thousands inhabitants. This means that "the Aymara have up to 3 times more chances of dying of HIV infections."(7)

In Venezuela, the Venezuelan Institute of Scientific Research [Instituto Venezolano de Investigaciones Científicas] and the Institute of Biomedicine [Instituto de Biomedicina] of the Universidad Central de Venezuela(17,18) carried out research studies in 26 Warao communities from the Orinoco Delta, and found that the virus was present in 9.55% of the inhabitants of eight communities, which represents a high prevalence rate considering that, throughout the country, it is 0.56%. The most affected community is Usidu with a prevalence of 21.6%.(8)

In the case of Panama, the 2007-2010 Multi-Sectoral Strategic Plan for HIV and AIDS Priorities [Plan Estratégico Multisectorial de VIH y Sida Prioridades 2007-2010], drafted by the Ministry of Health of Panama, reports that the epidemic is mainly centered on men that have sex with other men, sex workers and the indigenous communities of Ngobe-Emberá and Kuna, the latter with a prevalence that is twice as high as that estimated for the general population.(19) For the period 2001-2008, Panama had an accumulated rate of HIV cases of 136.8 per 100,000 inhabitants based on the 2004 population census, and among Kuna Yala region was of 234.9, being the most affected region after Colón.(20) Other sources(21) report that the HIV incidence rate in the Kuna Yala region is 10.2 (per 100,000 inhabitants) and in Ngobe-Buglé region is 8.4, holding the third and fourth places at national level. On the other hand, in the project "Strengthening Transgender Leadership" [Fortalecimiento de Líderes Transgéner@s] of the Kuna ethnic group of Panama, 101 screening tests were carried out on an Omeggid transgender group, 12.9% of whom were HIV positive.

In Ecuador, a research study(12) showed that, between 2002 and 2013, in the Morona Santiago region, located in central-south Amazonia, which has a 50% of indigenous population, there was an increase of 680% in HIV cases. Of the registered cases, 50% corresponded to the indigenous population of the Shuar nationality, most of which was located in that region.

In Brazil, the first case of AIDS among the indigenous population was reported in the state of Mato Grosso in 1987. Between 2000 and 2008, 94 cases of indigenous pregnant women with HIV were registered in the country. Until 2008 – based on the integration of different databases of available information systems – 624 cases of AIDS were identified and reported in the indigenous population. According to the records of the "National STD and AIDS Program", there was an increase in the incidence of sexually transmitted diseases and AIDS among the indigenous people living or regularly visiting the urban areas – especially those who live in the periphery of the urban centers – and among the inhabitants of the small villages in the indigenous territories.(22,23) Based on the data

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available for 2005, the incidence levels of HIV in the indigenous communities account for 0.3% of the total number of reports in the country.(24)

A research study conducted in Bolivia, between 2011 and 2012, showed that 22% of the registered cases were of people self-identified as indigenous – 32% of whom were young adults between 20 and 29 years old – and highlighted that the levels of prevalence among those young adults were higher than those for non-indigenous young adults.(25)

In Mexico, some approximations were made in relation to the impact of the HIV epidemic on the indigenous people; among them, one of the retrieved research studies includes a test for the rapid detection of anti-HIV antibodies. These findings are of great importance since they give evidence of the HIV impact on the indigenous peoples, at least in Sonora.(26) According to this multimethod study, the researchers worked in 19 indigenous communities of the Navojoa, Etchojoa and Huatabampo municipalities. The sampling process of the locations was randomized and probabilistic, and recruited 530 participants who were assigned to two groups: non-migrants (380 participants) and migrants (150 participants). This study confirmed the presence of HIV in five participants (three men and two women), accounting for a point prevalence of 0.94%. This may represent two situations: first, that HIV prevalence in the indigenous community in Sonora was eight times higher than at national level, or, second, that the prevalence at national level is underestimated due to the lack of timely detection strategies. HIV prevalence in the local population, with no migratory background, is 0.5%, while for the migrant population is 2% under vulnerability and migratory conditions. This is four times higher compared to the population of the State of Sonora.(26)

In Colombia, the National HIV/AIDS Plan 2008-2011 of the Ministry of Health reported that the indigenous peoples and displaced persons are populations at risk and mentioned that in Amazonia there is a high mortality rate (4.76) due to AIDS.(27) Zambrano et al.(28) documented that, in the department of Antioquia, the first HIV case was detected in an indigenous person in the year 2000, in the Embera Chamí community of Cristianía, Jardín municipality, and that since then a total of 10 cases had been reported, half of whom had died, mainly, due to the lack of early detection and care.

In Honduras, a research study carried out by the Pan American Health Organization and the World Association for Sexual Health(14) reported that the Garifuna and Miskito peoples, located in the Atlantic Coast of Honduras, were the most affected groups. Furthermore, in the case of the Miskito, in the Gracias a Dios department, over a period of ten years, 135 indigenous people were infected with HIV, and 17 adults and 5 children died of AIDS. Considering the number of stable couples and possible contacts, the researchers estimated a figure of "380 people exposed, accounting for 11% of their population, which could mean that 11% of this community are prospective HIV carriers".(16)

In Nicaragua, a research study of a regional nature conducted in Central America in 2004 provided epidemiological evidence on prevalence and high social vulnerability towards HIV infection in some ethnic groups of the country. In that year, researchers found a prevalence of HIV among the Sutiaba communities in León and Chinandenga of 9.9%, 4.9% between the Miskito and the Mayagna in the North Caribbean Coast Autonomous Region (RAAN) [Región Autónoma del Atlántico Norte] and 9.9%(29) among the Creole, Miskito and Garifuña communities of the South Caribbean Coast Autonomous Region (RAAS) [Región Autónoma del Atlántico Sur]. It should be mentioned that, in both regions, in 2004, the general HIV prevalence was 47.1 per 100,000 people for the RAAS, and 25.7 per 100,000 people for the RAAN.(30)

In Peru, since 2010, there is a regulation that states that the ethnic origin should be mentioned in the clinical record of those patients diagnosed with HIV; however, this has not been implemented so far. Nevertheless, there are some specific research studies on the subject. In 2004, a seroprevalence study of HIV and syphilis was conducted in

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an indigenous community, the Chayahuita, of the Amazonia, in the Loreto department, which reported a seroprevalence of 7.5% for HIV in adults, and 6.3% for syphilis.(31) In the results of the PREVEN project,(32) in 2007, it was mentioned that there is a high HIV prevalence (1.5%) among men and women in the cities of the Amazon rainforest, Puerto Maldonado and Yurimaguas.

In Guatemala, a research study carried out by the Pan American Health Organization and the World Association for Sexual Health(14) highlights that, in 2003, HIV cases had significantly increased, especially in the Southwest of Guatemala, where 60% of the inhabitants are Mayan, and on the Pacific coast, which is a region with a large history of indigenous migratory waves. Another research study conducted by UNAIDS-Guatemala in 2010 confirmed an increase in HIV cases among the Mayan population, with one out of five new registered cases.(33) The latest known epidemiological data disaggregated by ethnicity correspond to the year 2013, when it was observed that 21% of the people suffering from HIV in Guatemala were Mayans.(34) In some specific cases, the percentage seems to be higher, as registered in the major comprehensive care clinic of Quetzaltenango, the "Dr. Isaac Cohen Alcahé Comprehensive Care Clinic" (Clínica de Atención Integral Dr. Isaac Cohen Alcahé), which, in 2007, registered that 71% of the patients suffering from HIV belonged to the Maya-Quiché, Mam and Cachiquel(35) ethnic groups, in a department where, in 2012, 51.7% of the population was indigenous.(36)

From the perspective of the differential rate of HIV prevalence, incidence and mortality, we consider that these research studies, of a micro-level type, cannot be generalized at a statistical level, as the samples were small, thus involving many problems related to over or under registration. In some cases, such as in Ecuador, the alarming difference that the new records imply is due to the fact that, for the first time, disaggregated epidemiological data started to be collected. In other cases, the high prevalence of key indigenous groups, such as the transgender population in Panama, may be analogous to that of non-indigenous key population groups, pointing to certain dynamics of shared social vulnerabilities. Nevertheless, crossing the currently scarce quantitative material with the qualitative material, we can consider that the differential epidemiology (compared to the national and regional median) of the registered morbidity and mortality reveals a warning sign that highlights multilevel determinants that need to be studied closely, considering, as the fundamental exploratory axis, the differential vulnerability related to the ethnic condition.

Risk factors and sociocultural determinants in HIV infection

The findings from the analyzed material highlight different dimensions regarding the sociocultural determinants in HIV infection, which we have classified into four groups: ethnicity and racism; migration and poverty; female vulnerability; and sexuality and cultural conceptions around HIV.

With regard to *ethnicity and racism*, being indigenous has several implications with respect to social vulnerability in HIV prevention: not exercising the necessary sexual rights to achieve a sexual life without health risks, the right to sexual education and information, the right to non-violence by virtue of one's gender-sexual identity, the right to access sexual and reproductive health care services, the right to non-discrimination, equity and decent treatment by the majority of the population in institutional settings and in everyday life; and, especially, the right to decent health care service without discrimination.(11)

Migration and poverty are two very important determinants for the understanding of HIV risk and vulnerability practices. The indigenous communities have a high mobility rate.(15) Although migration is not a risk behavior, it is a vulnerability factor for HIV. In the migratory processes, the sexuality of some men and women changes while they are outside the community and the control of their family, be it for loneliness, experimentation or necessity, and may lead to creating bonds and physical contact with many different social groups and situations that favor risky behaviors – violent, forced or consensual but unprotected sex – that may lead to sexually transmitted infections, including HIV, against which they have very few means of protection and a significant lack of awareness of these diseases and their prevention. For this reason, many of them return to their communities to die of AIDS or are expelled from them due to this health condition.(12,13,37)

In relation to female vulnerability, in the indigenous communities there is a significant disparity between genders, which is grounded on what are known as customs and traditions of the indigenous communities that, as demonstrated in several research studies(38,39,40,41,42,43,44,45,46) carried out on some native communities, are discriminatory and tend to subordinate women who, on a daily basis, experience the effects of male domination, which goes hand in hand with traditional gender behaviors.(6) This can be seen in forced marriages and maternity, family and community violence, unsafe sexual practices of their partners, limited access to their sexual and reproductive rights, the lack of decision over these rights, girl trafficking, rape, psychological, physical and sexual violence, gender violence leading to inequity, legal and economic disadvantages regarding housing, social development, sexual and reproductive health, and education, as shown by research studies from Mexico,(11,47,48) Chile,(49) Bolivia,(50) Ecuador, Guatemala and Peru.(51) Such gender behaviors place indigenous women in a situation of great vulnerability towards HIV infection

In relation to HIV-related sexuality and cultural conceptions, in general, but mainly focusing on the female population, there is a lack of information and knowledge with respect to sexuality. Since it is still considered a taboo topic, there is no intergenerational dialogue on the subject, which includes the prevention of pregnancy and HIV, among other sexually transmitted diseases (STDs). The customs and traditions in relation to social and sexual gender roles determine the conceptualizations and practices regarding virginity, pairing, maternity and sexual practices.(50,51) There is a generalized belief among women – regardless of age – that fidelity to their partners is a protection tool, as many times they ignore or prefer to ignore the extramarital sexual practices that their partners have without protection during the migratory processes, permitting unprotected sexual relations with them upon their return, which dangerously exposes them to HIV infection and to vertical transmission. Considering that homosexual practices are not accepted, some men lead a double life and have to hide their preferences, tastes and practices for fear of stigmatization, discrimination and community violence. There is a widespread social representation that points to women as the main carriers and transmitters of STDs and HIV, thus becoming the main target for stigma and discrimination, in addition to all the problems they already have.(2,16,48,50,51)

Broadly speaking, for the indigenous peoples, HIV is conceptualized as a "new disease", "foreign", "from the others", "from white people", "external to the community". The epidemic is neither a relevant nor a priority issue, but rather a distant and external "misfortune" that may threaten but still has not reached them.(49,52,53) This invisibility constitutes a vulnerability factor because it does not allow them to perceive the situation as a risk. Moreover, there is a generalized lack of awareness about the biomedical explanatory model(54) of the virus and its modes of transmission, prevention, diagnosis and treatment. Even those who have a certain level of knowledge of the matter – most of them young men – have access to fragmented information that prevents them from understanding the disease in its different dimensions. Women have a lower biomedical knowledge of STDs, in general, and HIV, in particular, for example, in the case of Ecuador(55) and Mexico.(56) It is important to mention that, with some exceptions, sexual health campaigns aimed at this population are almost nonexistent.(53)

The explanatory model that the actors in the different studied contexts have in relation

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to HIV acquisition is mostly related to sexual access, principally linked to extramarital relationships, resulting from their access to sex work services, to sexual relations with persons that are "external to the community" or migrants. In turn, there is a wide variety of interpretations, unrelated to a biomedical perspective, about HIV acquisition that refer to different ways of understanding the body, such as fluids and smells (sweat, saliva, odor, blood, semen, breast milk); curses/witchcraft; weakness of the body and community life; insect bites (mosquito); taboos and transgressions of rules; sharing toilets, clothes, or the same plate and utensils with people with HIV; shaking hands or sharing the same seats, among others.(53, 55,57,58)

Another remarkable consensus that was evident in the materials surveyed is the scarce – or even nonexistent – use of condoms. To illustrate this situation, we selected, among a large number of materials, a research study carried out in Mexico involving 2259 indigenous people, of whom only a low 5% answered affirmatively that using condoms is a protection measure, while half of the sample reported that they have never been taught on how to use them.(53) A similar situation was also reported in the Qom (Toba) communities in Argentina.(52)

The main argument to justify not using condoms refers to "tradition" and "the natural habit". Other factors that hinder their use are the different cultural conceptions such as the loss of pleasure/sensitivity, the influence of religion that condemns their use, their rejection for considering them unnatural/artificial, the distrust as to their effectiveness, the loss of masculinity/virility, their association with infidelity or sex work, the alleged damage they cause to a "woman's womb" and other health issues, the lack of awareness regarding the existence of the condom, and, logically, the obstacles to access it. There is also the belief that it is exclusively a contraceptive method, and not a means of protection against STDs. Finally, in certain communities, discussing the use of the condom is taboo, even for health promoters and community leaders themselves: the latter are the only ones authorized to decide whether the issue should be addressed.(50,51,57)

Access and timely care in health services: HIV tests, condoms and antiretroviral drugs

The conditions of access to condoms, the rapid test for a timely detection and the antiretroviral therapy are some of the difficulties to access the health services, in general, and sexual and reproductive health care, in particular. The analyzed material shows that, in most of the documented clinical contexts, the HIV test is nonexistent, generally, because this test is never made available to the clinics in the areas where these peoples live.(59,60) When there is a certain knowledge about HIV and its detection, the demand for quick detection tests is also nonexistent due to several reasons, among which we find the fear of becoming stigmatized and discriminated by the community(28,29) for being a positive HIV and the limited cultural relevance given to the epidemic at a preventive and health care level.

In several indigenous communities, there is evidence of stigmatization and discrimination towards people suffering from HIV. One form of discrimination is the expulsion from the community due to their health condition. Problems derived from the lack of confidentiality within the community have also been observed towards people affected by the virus, which has a strong impact on health care and adherence processes, as the fear of being marginalized or violated in their rights leads them to hide the disease.(14,16,61)

According to the analysis of the collected material, the awareness of the existence of antiretroviral drugs by the indigenous people in Latin America is indeed scarce in general, which is mainly evidenced in rural areas. The most optimistic documents report a case, in Guatemala, in which people who know about the treatment are just over 43%.(62,63)

One of the main problems in accessing the antiretroviral therapy (ART) and the CD4 and viral load tests is their centralization in the cities and in secondary and tertiary healthcare level hospitals and clinics. Sometimes, the indigenous users, due to their deteriorated health condition and their need for a translator, must be accompanied by one of their relatives. This increases the cost of the trip, which they can seldom afford. Two documented cases in research studies are, on the one hand, the ART offered in San Cristóbal de las Casas and the CD4 and viral load tests in Tuxtla Gutiérrez (Chiapas, Mexico), which show the difficulties undergone by users from remote communities to get to these places, such as in the case of the Lacandon jungle, located ten and twelve hours away.(64) On the other hand, in Ecuador, CD4 and viral load tests in the region of Morona de Santiago are available in the city of Cuenca located at a distance of more than eight hours from, for example, Macas, the capital city of this region, and the communities closest to the Amazon.(12) The scarce data available that document adherence to the antiretroviral therapy of indigenous people with HIV in Latin America show a high rate of treatment withdrawal. The mentioned research study focused on Altos de Chiapas (Mexico) shows that, of the 122 patients that were discharged from hospital in 2012, in the "Antiretroviral Surveillance and Logistic Administration System", considering that only the last two years since the creation of the program were taken into account, registered a total of 32 patients who withdrew the antiretroviral treatment, most of whom were indigenous people. This correlates with 43% of the total number of indigenous patients (defined as such for speaking an indigenous language) registered in this program.(64,65) In Panama, a study carried out in 2009 involving the Kuna showed that only 60% of the people with HIV had access to the ART, and that only 20% adhered to the treatment. In turn, this study mentions that of all the Kuna patients who were tested for CD4 and viral load, only 60% received the results.(19) The absence of follow-up visits, especially in the most remote communities, and the inappropriate way of conducting them in terms of the use of ambulances and medical service clothing, thus deepening the visibility, stigma and discrimination within the communities of residence of the user, is another documented issue in many Latin American countries.

Obstacles in the provision of the antiretroviral treatment and timely follow-up

The main obstacles related to the adequate ART and health care provision are of three types. First, those of a communicative, linguistic and cultural nature, related to the absence of a common language and an explanatory model of the health/disease/care-prevention process that is sufficiently shared between the physician and the patient to make the clinical appointment feasible. Second, those related to stigmatization and discrimination by the health care providers, operating through their social representations, and their correlation in their health care practices, with respect to the social and cultural background of the user. Third, those linked to the dominant biomedical care approach and its imposition and intolerance in relation to other interpretations of the health/disease/care-prevention process.

Some of the consequences, in terms of the unequal access to the antiretroviral treatment, associated with the lack of linguistic and cultural translators and interpreters in health care centers are related to the reactivation of stigma and discrimination through a breach of confidentiality. The absence of a common language and an explanatory model of this process shared by the patient and the physician raises the need for the presence of linguistic-cultural translators during the clinical encounter.

Linguistic translation is essential for imparting information and ensuring the success of the encounter, in this case, between the health care provider and the patient. Nevertheless, in this situation, the attempts of cultural translation should consider the inequality of power and its ways of operating through, for example, racism, and the many explanatory models of suffering and care. In the case of the indigenous peoples, the scarcity of cultural codes shared by the actors present in the medical arena is another element to be considered, along with the linguistic element, as the juxtaposition of excluding factors such as those of a structural, social, economic and cultural nature – like racism, discrimination, the characteristics of the organizational culture of biomedical care, among others – has a differential impact on the access and type of health care provided to this community.

An example of this is that, in most Latin American health care centers where ART is provided, there are no professional translators or interpreters, and the only way of having a viable medical encounter, when the patient does not speak the dominant language, is through an informal translator. Generally, a medical appointment that includes the presence of a translator, as a prerequisite formalized or not by the physician, requires a family member of the patient or a health care provider of the community to make all the necessary arrangements to set such appointment, which may have various implications in terms of the breach of confidentiality and its potential impact on the patient's social vulnerability.(64)

The intercultural approach in the provision of ART is almost nonexistent, as mentioned, for example, in studies carried out at regional level in Central America(29) and in the specific cases documented in Guatemala(62) and Bolivian Amazon.(66) However, the different proposals that we surveyed, with a remarkable consensus, highlight the need to include a more intercultural approach in health care services, in general, and in the response to HIV, in particular. In turn, we demonstrated that most of these materials do not define or specify their understanding of this concept/approach.

We consider that, in the last few years, the idea of "interculturality" has become a sort of "politically correct" term, a "common place" that is used frequently and readily during the debates that discuss the ways in which the different cultures should interact with each other, in this case, in the health care field. However, when this concept starts to be problematized, we realize that not all of us think or understand the same when talking about interculturality.

Through our research study, we showed that the concept of interculturality, frequently adopted by public health policies in Latin America, is related to the inclusion of a "culture of the cultural,"(67) which is based on stereotypes of the representations and practices of the user that, far from conceiving biomedicine as a culture that is susceptible to be relativized and transformed, in the search of an improvement of its effectiveness and democratization, only intends to interculturalize the subordinate by adopting static and stereotypical assumptions. Due to the poor quality and lack of warmth in the treatment of indigenous patients, added to the absence of training of the health care personnel on HIV, the lack of translators, the fear of a breach of confidentiality by these professionals and the eminently biomedical approach – see, for example, the research studies conducted in Central America(29) and Bolivia(68) – it is common to perceive the distrust of the indigenous users towards the institutions that provide the ART and their representatives.

DISCUSSION: CHALLENGES IN PUBLIC POLICIES, THE CIVIL SOCIETY AND ACADEMIA

This article is the result of the first research study conducted on HIV and the indigenous peoples in Latin America. Due to its nature of review and analysis of the situation of prevalence, incidence, prevention and health care, based on all the collected documents, we spark a debate in and from these fields of knowledge where dialectically opposed standpoints converge, both in theory and practice, which are summarized in the expressed or implied invisibility or not of the articulation of the health determinants of a social, political and economic nature with the ethnicity/race variable. Furthermore, we focus on the implications of such visibility or invisibility and its operational modalities, in contexts such as indigenous communities, academic research, public policies and civil society, in terms of the violation of human individual and collective citizen rights.

Since 2003, many international bodies and organizations such as UNAIDS, PAHO, World Bank, WHO, FCI Bolivia and SIPIA itself have warned about the spread of the epidemic among the indigenous peoples. To do this, they have many proposals and recommendations of various scopes, from structural problems to intermediate determinants of health, with a broad thematic range that, conceived from a comprehensive perspective, we consider relevant in our analysis for the regional context of Latin America. Although it is a great challenge to continue making adequate and effective proposals on HIV prevention-care and control in the indigenous communities, assuming that the knowledge of the behavior of the epidemic is still scarce in the many different socio-cultural contexts of the region, the non-implementation of those specific and focused recommendations poses serious questions. In this sense, we ask ourselves the following questions: What has been done in all these years with regard to these alarming diagnoses? What public policies have been promoted in those contexts in which so many recommendations have been proposed?

We know that it is impossible to implement a public policy without an economic foundation to support it; for that reason, the other major challenge clearly linked to the implementation of the recommendations lies in its financing. Within this framework, and beyond the valuable local and focalized experiences that were carried out, it is necessary to answer another question, what budget have the international health organizations and the national states assigned to this issue?

Along with the different recommendations to stop the spread of the epidemic among the indigenous populations and improve prevention, care and timely follow-up, the civil society, in particular, has implemented a number of practices with a more practical approach. This means that they have attempted to modify the current situation in this population by implementing interventions of different types in the areas of epidemic prevention and care. These interventions are very diverse and range from workshops and focus groups, specifically, on human rights, to attempts to implement intercultural methodologies to improve access to the antiretroviral therapy. With regard to specific public policies, the only Latin American country that has implemented a differential health care model that comprises the specific approach towards sexually transmitted diseases, HIV and AIDS for the indigenous population is Brazil, where control policies were implemented within the framework of an indigenous health subsystem.(61) What characterizes this differential health care model for the indigenous population is that it is currently divided into 34 special indigenous health districts [distritos sanitarios especiales indígenas]. The proposed model for these districts is characterized by placing the emphasis on health promotion, health services in the villages themselves, the implementation of programmed demand, and of national prevention programs. However, the analyzed material does not allow us to understand the impact that this model has had in HIV prevention and care in the indigenous population of Brazil.

We insist on the need to adopt a work perspective that starts from the conditions under which HIV makes its appearance, becoming a major issue in the indigenous communities. We are concerned about the way several HIV-related research studies only "praise" the cultural dimension of the native communities and do not focus on the living conditions that cause deterioration, disease and death, which tend to overshadow the conditions of poverty and the inequality relations behind the problem.(69) In this sense, and in this context, these actions would seem to be a "correct" response; however, they fail to address the social and economic origins of the susceptibility to the infection.(70)

In this sense, along with the implementation of the recommendations to tackle the spread of the epidemic by means of the sociosanitary intervention, the main challenge consists of solving the structural problems that the native communities suffer, and developing a new intercultural policy that has an impact on their life, health, education and working conditions, as well as on the access to their own territories. Without these measures being detrimental to the political responsibilities of the States and international organizations mentioned, we deem it necessary to develop the conditions for the indigenous communities to take control of the process of health/disease/care-prevention and control, in this case, in relation to HIV and sexual and reproductive health care, and to participate in the collective management and decision-making process towards biomedical prevention and care. It should be mentioned that, in this matter, these men and women are also subjects of law and not just passive recipients in an endangered survival situation in which necessity becomes a virtue. They are individual and collective actors that have a lot to say, contribute and decide with regard to their own well-being and to that of the whole population.

On the other hand, we have observed that in the so-called customs and traditions many elements have been observed that negatively impact the spread of the epidemic among the indigenous peoples. We consider it problematic that social scientists, financing agencies, civil society organizations, governmental bodies and public servants involved in this matter still reproduce an extreme perspective of defense with regard to customs and traditions so as to preserve a mystified culture. We believe that it is essential to provide the necessary elements to adopt a dynamic concept, in which men, women and sexual dissidents have the right to modify that culture and start being recognized as valid interlocutors and subjects of law within their communal framework.

Moreover, the indigenous communities need information, guidance and training regarding the biomedical explanatory model of HIV, an epidemic that did not previously exist among them, in a framework based on exchange and peer learning of experiences and interpretations of the health/disease/care-control process of this health issue.

Accepting the presence of HIV within the indigenous communities is a reality that, for many traditional authorities of the region, can no longer be procrastinated. We consider that it is essential to provide the support and promotion, for these actors and all members of the community, of non-directive and consensual initiatives for study and intervention, and to foster spaces for dialogue – including those involving different generations – of respectful knowledge with regard to differences on sexuality, gender relationships, discrimination, love and sexual diversity and HIV, so as to promote respect for the Human Rights of women and sexual dissidents.

The inhabitants of the indigenous communities have the right to decide whether or not to include such topics on their agenda, as well as whether or not to implement the use of the condom in their love and sexual practices, although this decision should be reported and reflected upon as to its meaning and implicit costs that it would demand. For this reason, public policies should especially ponder this issue, since it is a multidimensional vulnerability that should be addressed from different perspectives and social fields: both by civil society organizations that work in response to HIV, Human Rights and against homophobia, and by those who work in favor of the rights of the indigenous peoples, and against racism and discrimination. Naturally, one of the responsibilities falls on the authorities and leaders of indigenous peoples. As expected, this implies several challenges, the most important and essential of which, perhaps, is that the communities assume the challenge of discussing sexuality and, particularly, sexual diversity. The role of academia is to provide the theoretical and analytical knowledge to better understand the vulnerability and the ways to fight against it.

Ignoring the ethnic specificity in health research studies, in this case, on HIV, is to hide racism as an organizing and reproductive principle of the social structure in a sort of segregationist assimilation/homogenization. It denies the culture so as to even up the way of addressing a health issue that affects both the mestizo and the indigenous

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population, and delves into the segregation caused by the differential impact of HIV on a historically marginalized community such as the indigenous population.

Making this HIV epidemic visible among the indigenous communities in Latin America, through empirical quantitative and qualitative data, does not exempt them from potential discriminatory uses – for their cultural background – and stigmatizing – for their health condition – of the information gathered during the process. We consider that, in order to face the risks of the culturalization of the epidemic in scientific production and decision-making, we will not be able (as researchers) to control the future procedures resulting from the decontextualization of this data, as it is necessary not to isolate the ethnic variable, but to understand and explain it in articulation with other types of socioeconomic and political variables, such as gender-sexual identity, poverty, migration or symbolic violence. In turn, it is essential to highlight the ways in which racism makes social inequity invisible, by denying ethnicity as a category of analysis of reality, and how in this situation being an indigenous person, a woman, a sexual dissident, a poor or marginalized individual may expose to social, gender-centered and cultural determinants that result in a differential vulnerability for HIV acquisition.

CONCLUSIONS

The scene is bleak, sad, worrying and shows the huge debt that still exists with these populations. To exclusion, marginalization, racism, poverty, hunger, diseases, lack of work and educational opportunities, lack of information concerning their sexual and reproductive rights, we have to add HIV and its terrifying consequences in a scenario of invisibility.

Finally, as vulnerability to the epidemic is directly related to the lack of respect for fundamental human rights, which in turn are also permeated by gender constraints and cultural matrices, only when necessities are acknowledged, can they be changed and reoriented for the benefit of the protagonists themselves, so as to develop public policies in the field of prevention, care and damage mitigation, as in this social and cultural context, the threat of an epidemic that is far more severe, complex and much broader in its scope than expected so far can be envisaged. The ethnic imperative is unavoidable and urgent, most Latin American countries are considered multiethnic and multicultural; therefore, this principle should be upheld: health is a right and the indigenous peoples should enjoy it, which represents a challenge for all of us.

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