


Social movements and public policies - action of the NGO *HTLVida*


Movimentos sociais e políticas públicas – atuação da ONG HTLVida

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Abstract

In contemporary history, several forms of civil society organizations have stood out in the struggle to expand rights. Non-governmental organizations dedicate themselves to extending the rights of the group for which they were created. This study shows the work of the *HTLVida* to NGO introduce HTLV to the governmental agenda of Bahia State, Brazil, and to extend rights for this population. HTLV is a retrovirus affecting T lymphocytes which can cause neurological and hematological diseases, among others. Brazil has the highest absolute number of cases and Bahia is one of the states with the highest infection prevalence. We found that several factors contributed to including the topic in the Bahia government agenda and the subsequent implementation of rights; among these, the strong militancy of individuals infected with the virus in the *HTLVida* group. Regarding their achievements, we highlight the structuring of a municipal outpatient clinic, the creation of the Municipal Day to Confront HTLV, and its inclusion in activities related to STIs in health departments. Despite significant advances, this social movement still needs to persist to mobilize the expansion of social rights for people living with HTLV.

Keywords: Social Movements; Deltaretrovirus; Public Policies; Infectious Diseases.

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Resumo

Na história contemporânea, diversas formas de organização da sociedade civil têm se destacado na luta por ampliação de direitos. As Organizações Não Governamentais são instituições que se dedicam a reivindicar ampliação de direitos para o grupo pela qual foram criadas. Neste artigo apresentamos a participação da ONG HTLVida no processo de introdução do tema HTLV na agenda governamental na Bahia e militância por ampliação de direitos para esse público. O HTLV é um retrovírus que afeta os linfócitos T e pode causar doenças neurológicas, hematológicas, dentre outras. O Brasil é considerado o país com o maior número absoluto de casos e Bahia é um dos estados com maior prevalência da infecção. Constatamos que vários fatores contribuíram para inclusão do tema na agenda da Bahia e consequente implementação de direitos, dentre esses, a forte militância de indivíduos infectados pelo vírus no grupo HTLVida. Quanto às conquistas, destacamos a estruturação do ambulatório municipal, a criação do Dia Municipal de Enfrentamento do HTLV e a inclusão do tema nas atividades referentes às IST nas secretarias de saúde. Apesar de significativos avanços, o movimento social ainda precisa persistir na mobilização por ampliação de direitos sociais para pessoas vivendo com HTLV. **Palavras-chave:** Movimentos Sociais; HTLV; Políticas Públicas; Doenças Infeciosas.

Introduction

Currently, various forms of civil society organization, such as social movements, trade unions, professional and residents' associations, political parties, non-governmental organizations (NGOs), and interest and pressure groups have become key actors to fight for rights expansion. Kingdon (1984) deems pressure groups one of the non-governmental actors seeking to interfere in the process of forming governmental agendas. This study analyzes the participation of these organizations in the conformation of public policies and the experience of HTLVida from Bahia in fighting to expand the rights of people living with the human T-cell lymphotropic virus (HTLV).

HTLV is a retrovirus which affects T lymphocytes. In 1980, HTLV-1 was identified as the first retrovirus associated with cancer in humans (Poiesz et al., 1980), after it was isolated in a patient with t-cell malignancy. In 1982, HTLV-2 was found and described as rarely associated with clinical manifestations (Kalyanaraman et al., 1982). In 2005, HTLV-3 and HTLV-4 were isolated in individuals in Cameroon (Mahieux; Gessain, 2009), without having been associated, so far, with any disease.

The World Health Organization (WHO) recognizes HTLV-1 as an etiological agent of adult T-cell leukemia/lymphoma) and of tropical spastic paraparesis/HTLV-associated myelopathy, the two main diseases related to the virus. Included in the sexually transmitted infections (STIs) group, it can lead to the onset of neurological symptoms, such as overactive bladder, erectile dysfunction, hyperreflexia, and spasticity even in the absence of tropical spastic paraparesis (Souza et al., 2012). In addition to hematological and neurological diseases, other morbid conditions associated with HTLV-1 infection include ophthalmologic manifestations, such as HTLV-1-associated uveitis; skin manifestations associated with immunodepression (such as infectious dermatitis); urinary and joint manifestations; and infectious (such as tuberculosis) and parasitic diseases such as scabies and strongyloidiasis (Romanelli; Caramelli; Proietti, 2010).

A study conducted in blood banks in Brazilian state capitals and its Federal District showed that HTLV-1 infections occurs heterogeneously (Catalan-Soares; Ram-Proietti; Proietti, 2005). The country has the highest absolute number of infected individuals, with an estimated prevalence of 800,000 seropositive people (Gessain; Cassar, 2012).

Despite relevant studies from research groups and the greatly worrying Brazilian estimates, the country still lacks national and comprehensive policies to cope with the infection. Ministry of Health control and prevention actions are limited to determining serological screening in blood banks (Brasil, 1993), publishing ordinances regulating transplants for and from seropositive individuals (Brasil, 2009), and producing technical materials for professionals working in blood banks and public health laboratories (Ministry of Health, 2014).

HIV-positive patients have obtained several achievements, regardless of their working conditions and/or socioeconomic status, such as: exemption from income taxes (in case of retirement or pension income), a severance guarantee fund (FGTS), free public transportation, and early court orders, among other benefits.

HTLV infection is still unlisted as a serious and chronic disease in the legal norms guaranteeing rights to specific groups, such as HIV-positive individuals. People living with HTLV may require free public transportation, for example, if they also have leukemia/lymphoma or neurological sequelae due to oncologic diseases and/or physical disabilities (but not by infection). This inequality regarding patients' rights refers to the importance of social

mobilization to include subjects in sectoral agendas to expand actions and conquer rights for people living with the virus.

We show the important participation of social movements in the struggle for public policies and expansion of rights. We also discuss how organizations of people living with HLTV became references for groups to adjust and act toward other demands.

Regarding their militancy for the rights of people living with HLTV, we only found organizations working toward them in Rio de Janeiro and Bahia, the NGOs *Grupo Vitamóre* and *HTLVida*, respectively. We characterized the latter as a fundamental pressure group for the inclusion of the theme in government sector agendas which would favor the expansion of actions and care services for this public in the state of Bahia.

Methodology

This study on the participation of organized social movements in elaborating government agendas belongs to a larger research on the introduction of HTLV in the Bahia and Minas Gerais States government agendas, two pioneers in the development of public policies aimed at people living with HLTV. This study was submitted to the ENSP/FIOCRUZ Research Ethics Committee and approved by CAAE: 87600218.4.0000.5240.

The multiple streams framework in Kingdon (1984) was used as a theoretical and analytical reference, and guiding questions were developed for each of its categories, according to Chart 1:

Chart 1 – Multiple streams framework and guiding questions

| Categories | Guiding questions |
|------------------|--|
| Problem stream | When and why has HTLV been identified as a problem? What events preceded it? What factors motivated actors' attention? |
| Solution stream | What solutions/alternatives have been proposed? Which have achieved consensus? What ideas were opposed or discarded? Which actors were involved in the process, and which were predominant? |
| Political stream | What was the political context that favored the entry of the problem into national and local agendas? Were there social movements or organized groups (organized political forces)? Have there been changes in government (changes in party agenda)? What influenced governmental decisions? |

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Chart 1 – Continuation

| Categories | Guiding questions |
|------------------------|---|
| Actors | Which governmental and non-governmental actors participated in defending HTLV proposals (public servants, parliamentarians, researchers, activists)? Did interest groups mobilize themselves? |
| Windows of opportunity | At what point did streams converge? How did proposals get on governmental decision-making agendas? How did policy entrepreneurs act? Which factors favored and hindered the approval of HTLV actions? |

Interviews and documentary research were adopted as data production strategies. Our field research was developed from September to October 2018. Actors who had participated in the political process of discussing and implementing actions to control and prevent HTLV were considered as our inclusion criteria, e.g., STI service/program managers and coordinators, healthcare providers, and activists.

All guests agreed to be interviewed and allowed themselves to be recorded after signing informed consent forms. In total, 20 semi-structured interviews were conducted with key actors, 14 of which were in Salvador (BA) and six in Belo Horizonte (MG). Regarding organized movement representatives, four subjects were interviewed in Bahia. No such organizations or militants were found in Minas Gerais. Interviewed subjects are shown in Chart 2 by type of representation.

Chart 2 – Survey participants by type of representation

| | Representation | Institution | Function | Training |
|---|--|--|---|--------------------|
| Bahia interviewees (14 participants) | Social Movement (4) | Salvador Municipal Health Council - BA | Women's rights activist, CMS-SSA member | Nursing |
| | | HTLVIDA NGO | NGO Director | No information |
| | | | Secretary, former NGO director | Psychology |
| | | FOBONG - Bahia NGOs Forum | Representative and articulator of NGOs/AIDS Bahia forum (Fobong); | Physical Education |
| | Healthcare provider (3) | Pharmacists' Union | Member of the pharmacists' union, former CES-BA advisor | Pharmacy |
| | | SAE Marismar Novaes (SMS-Salvador - BA) | Unit psychologist | Psychology |
| | | HTLV outpatient clinic at the UFBA Edgard dos Santos University Hospital | Unit nurse | Nursing |
| | Manager (7) | STI sector at the Municipal Health Department of Salvador - BA | Head of the STIs, AIDS, and Viral Hepatitis Monitoring Sector in the municipality of Salvador | Dentistry |
| | | Multidisciplinary Center for the Care of People with HTLV the Escola Bahiana de Medicina | Unit coordinator, Fiocruz Researcher, Full Professor at Escola Bahiana | Medicine |
| | | | Managing Director | Administration |
| | | SAE Marismar Novaes (SMS-Salvador - BA) | SAE Coordinator | Biology |
| | | HTLV outpatient clinic at the UFBA Edgard dos Santos University Hospital | HTLV Outpatient Coordinator, Researcher | Medicine |
| | | Bahia State Department of Health (SESAB) | Disease Coordination | Nursing |
| | Reference technique for HTLV in the state of Bahia | | Nursing | |

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Chart 2 – Continuation

| | Representation | Institution | Function | Training |
|--|---|------------------------|---|-----------|
| Minas Gerais Interviewees (6 participants) (6 participants) | Healthcare provider (3) | Hemominas Foundation | Hemominas researcher, professor at UFMG, infectologist | Medicine |
| | | | Infectiologist at SMS-BH and Hemominas researcher | Medicine |
| | | | Infectiologist at SES-MG and Hemominas researcher | Medicine |
| | Manager (3) | Hemominas Foundation | Former Hemominas coordinator, HTLV cohort officer 1997-2017 | Medicine |
| | | | HTLV Cohort Coordinator | Dentistry |
| | Belo Horizonte – MG Municipal Health Department | STI SMS-BH Coordinator | Nursing | |

A documentary research was conducted to survey discussions on HTLV in the minutes and agendas of meetings and deliberations of the Bipartite Interagency Commission, State Health Council, Legislative Assembly, Municipal Health Council, and City Council of the respective capitals between 2000 and 2018. Most documents were available online on the official pages of the respective forums.

Moreover, we asked their secretariats for unavailable ones, which were granted for this search.

Content analysis was the reference used to treat this material. Interviews were transcribed in depth and all the material, exhaustively read. In total, five general categories, 10 contextual ones, and registration units relating to our research objectives were identified (Chart 3).

Chart 3 – Study objectives and categories identified in the analyzed answers and documents

| Objective General | Specific Objectives | General Categories | Context Categories | Registration Units |
|--|--|--------------------|---|--|
| Analyze the governmental agenda on HTLV prevention and control in the states of Bahia and Minas Gerais | To find the scenarios, motivations, and main actors to prioritize HTLV in governmental political agendas | I. HTLV - history | 1. HTLV Discovery | First studies on HTLV Inclusion of HTLV in Ordinance No. 1,376/1993 |
| | | | 2. Research, teaching, and assistance institutions: a) HTLV Multidisciplinary Center (Bahia); b) HTLV/UFBA Outpatient Clinic; c) Hemominas Foundation (Minas Gerais) | History; access; strategies to maintain care; findings/search results |
| | | | 3. Clinical and epidemiological aspects | Confusion between HIV and HTLV; transmission routes; clinical manifestation in adults and children; prevalence; unreported/underreported disease; non-inclusion of HTLV in the list of neglected or rare diseases; stigma/prejudice; delivery guidance for positive women; need for prevention |

continue...

Chart 3 – Continuation

| Objective General | Specific Objectives | General Categories | Context Categories | Registration Units |
|-------------------|---|-------------------------------------|---|--|
| | To identify the factors favoring or hindering the formulation of an agenda and implementing actions to prevent and control HTLV in these states | II. Ignorance of infection | 4. Neglected, invisible, ignored disease | By healthcare providers; the population; and managers |
| | | III. Actions developed by the State | 5. Policies for people living with HTLV | Lack of direction from the Ministry of Health; pressure/factors to include the subject in governmental agendas; political interest/disinterest; justification for the development of actions |
| | Describe norms, strategies, and actions which have been implemented to prevent and control infections | | 6. Care network: (a) research institutions; (b) Municipal Health Department; (c) State Department of Health; and (d) others | Existing services/network organization; actions/strategies/planning; financing/resources for actions; partnerships between different sectors and agencies; multidisciplinary work; comprehensive service; testing pregnant women; testing other groups; non-breastfeeding guidance and infant formula supply; follow-up of a child of positive mothers; calling relatives of positive patients; difficulties (confirmatory examinations, underreporting) |
| | Describe norms, strategies, and actions which have been implemented to prevent and control infections | IV. Dissemination of the theme | 7. Training | Training professionals to assist and structure services |
| | | | 8. Health education | Educational actions for the population (campaigns, spread of educational material); dissemination strategies (including HTLV as an STI, presenting HTLV in events, disseminating it in the media) |
| | To identify the factors favoring or hindering the formulation of an agenda and implementing actions to prevent and control HTLV in these states | V - Social movements | 9. Social Mobilization | Importance of social mobilization to disseminate the theme; participation of the social movements in including HTLV in governmental agendas; inclusion of HTLV in discussion forums; lack of mobilization negatively impacting the implementation of actions |
| | To find the scenarios, motivations, and main actors to prioritize HTLV in the political agenda of governments | | 10. HTLVIDA NGO | NGO structuring; developed activities/actions; search for partnerships; recognition of the NGO work by other institutions |

CES: State Health Council; CIB: Bipartite Interagency Commission; CMS: Municipal Health Council; STIs: sexually transmitted infections; NGO: non-governmental organization; UFBA: Universidade Federal da Bahia.

Associativism and Public Policies

For Offe (1991), public policies result from the political system processing demands, as the State seeks to meet the demands of specific groups or broad societal sectors. According to Gerschman (1989), to understand the policy formation process, we must assess the relations between State and society and the influence of its various actors in negotiating and defending processes of a given policy. This relation involves conflicts of opinion, values, and interests.

Public policies, thus, result from political activity encompassing decisions of public authorities and social participation (Gerschman, 1989). Given the above, we should ratify the performance of the organized segments of society which are committed to defending rights since they play an important role in pressuring and interfering in the practice of public policies (Rua, 1997).

Several governmental and non-governmental actors participate in forming agendas. They seek to insert their questions to formulate or expand policies (Kingdon, 1984). Non-governmental actors include pressure groups, which may contain heterogeneous organizations with greater financial, technical, political, and administrative resources, such as churches, unions, professional categories, NGOs, well-known corporations (such as the Landless Workers Movement, the Student Movement, and the Single Workers' Center, among others), and institutions with few resources, such as residents' association; neighborhood group, and some NGOs.

According to Gohn (2013), their strategies of action differentiate social movements from NGOs. While social movements act by denouncing, mobilizing, marching, blocking roads, negotiating, bargaining (among other strategies), NGOs seek to assist the public for which they were created, despite their negotiating strategies. They constitute civil society institutions which differ among themselves by their organization and performance degrees, ranging from small groups (such as association of mothers from a neighborhood) to international institutions (such as Amnesty International and Greenpeace) (Pinto, 2006). They show financial

instability, surviving via donations, funding from international organizations or state resources.

According to Landim (1998), NGOs have private identities, autonomous institutions at universities, churches, and political parties, although they hold the latter as reference. They neither seek profit, philanthropy, charity or welfare nor are academic, although they use research and scientific data to support their performance, valuing information and technical skills. These organizations have political nonpartisan purposes. They are neither governmental (but maintain relations with the State either by pushing for policy formulation and rights expansion or collaborating to implement actions to offer services) nor replace political parties since they have fragmented actions and avoid exercising any political power (Pinto, 2006).

In addition to acting as a group of interests or pressure in decision-making bodies (Santos, 2014), NGOs often partner with organized social movements to create pressure groups against the government but may eventually partner with the State to propose policies and execute plans.

Pinto (2006) classifies NGOs into two groups, according to their motivations: those claiming rights for their members, for example, formed by Black people against racism, women against sexism, among others; and those who defend the cause of others, such as the homeless, orphans, drug addicts, victims of human rights and sexual abuse, among others. The author points out that, despite their social attributions, NGOs are unable to replace the public policy liability of the State as a regulatory and executive body.

The Brazilian redemocratization favored the organization of social movements, facilitating the creation of some NGOs and political parties. Pinto (2006) points out that, since the 1988 Constitution, the presence of civil society as a political actor has grown, whether by managing council policies or integrating demonstrations and pressure groups. In this context, NGOs have strengthened themselves with an important inclusive function in a society which excludes a large proportion of its members.

Gohn (2013) differentiates NGOs founded in the decades before and after the 1990s by two types

of associativism. According to the author, in the 1970s and 1980s, NGOs were autonomous and participatory institutions, originating in popular movements linked to the Catholic Church or the 1970s new unionism. These militant NGOs concerned themselves with strengthening the representation of popular organizations and building a popular democratic field. They supported social movements against the military regime, fighting to democratize Brazil, and demanding political, civil, and social rights. They scarcely dialogued with institutionalized public agencies, maintaining a confrontational posture against the State (Gohn, 2013).

According to the author, from 1990 onward, with the rights established by the Constitution of 1988, propositional NGOs partnered with the State to define forms of management, implement laws, participate in councils, and even provide services in unassisted areas, belonging to institutions from the “third sector.” Research on the participation of NGOs in public policies, conducted with federal managers (Lopez; Abreu, 2014), shows the complementary relation between the State and these organizations. Thus, during this period, street demonstrations decreased.

We now highlight the actions of these institutions in the beginning of the AIDS epidemic in Brazil and how they contributed to pressure the State for public policies to control the disease.

AIDS-coping NGOs as a reference to other associations

The history of the aids epidemic in Brazil begins with political demands to redemocratize the country and secure social and political rights. Segregating conducts, such as news of the disease as a “gay plague” and information that the virus could be hematogenously transmitted (rather than only sexually), contributed to public policies mobilizing civil society. Given this context, NGOs belonged to a social movement which consisted of progressive sectors, sanitarians, and other institutions and organizations acting toward the rights of people affected by the new epidemic (Galvão, 2000).

Existing groups, such as *Associação de Hemofílicos* (Hemophiliacs’ Association), *Atobá*,

and *Grupo Gay da Bahia* (Gay Group of Bahia), joined others which aimed to assist people living with the infection, disseminating information on its transmission and prevention. They consolidated themselves in AIDS/NGOs as pressure groups which claimed public policies to meet this recent demand (Daniel; Parker, 1991).

Between 1985 and 1991, the first aids organizations were created, in a period lacking any treatment for the disease. According to Silva (1998), AIDS NGOs developed bonds of social solidarity in their relationships with managers, researchers, and other NGOs. Militants simplified the technical language on the infection to democratize information and encourage prevention. We highlight *Grupo de Apoio e Prevenção à Aids* (AIDS Support and Prevention Group), created in 1985 in São Paulo; the Brazilian Interdisciplinary AIDS Association, founded in 1986; and *Grupo Pela Valorização, Integração e Dignidade do Doente de Aids* (Group for the Valorization, Integration, and Dignity of Patients with AIDS - Pela Vidda), founded in Rio de Janeiro. These three institutions aimed to receive, educate, and guide people with AIDS to reduce their exclusion and vulnerability. They also participated as pressure groups in governmental spaces during public policy-making (Galvão, 2000).

According to Villela (1999), the AIDS epidemic, on the world stage, inaugurates a new articulation model of health issues between the State and civil society by establishing partnerships and government funding for organized coping movements. Teixeira (1997) points out that the State recognizing this demand and involving socially excluded and stigmatized groups was fundamental to configure policies in subsequent years. From the production of the first antiretrovirals onward, organized civil society stood out in demanding legal compliance with the guarantee of medicine offer.

In this context, according to Kingdon’s classification (1984), visible actors’ participation, such as that of interest groups (including NGOs and state managers - high-ranking officials) and invisible actors (such as researchers, sanitarians, and healthcare providers) were also vital to give visibility to the theme and include it in governmental agendas. Subsequently, the Ministry of Health

was essential to discuss and approve laws to meet the growing mobilization in the face of the epidemic. These actors' actions made it possible to gradually structure the Brazilian policy to combat aids and expand the rights of individuals infected with HIV.

NGOs in the fight against HTLV

In the 1990s, patient groups began to organize themselves in different hospitals, encouraged by the creation of NGOs responsible for the rights of people living with HIV and by the healthcare providers, such as social workers and psychologists, who worked in these spaces (Valle, 2013). The author also emphasizes the social mobilization of people living with HTLV in the 2000s at Pela Vidda, an institution which served as a model for the creation of other Brazilian NGOs in the fight against aids, besides configuring a space for emotional, social, and legal support. Despite supporting other NGOs, Pela Vidda has specific attributions to support people living with HIV, making it important to create institutions specific to the HTLV cause.

Faced with the need to disseminate information about HTLV (transmission, prevention, and treatment) and expand patients' rights and access to health services, in 2007 and 2010, two organized civil society institutions were created, namely, *Grupo Vitamóre* in Rio de Janeiro and *Associação HTLVida* in Bahia.

In addition to the institutions in Rio de Janeiro and Bahia, we only found another: *Associação Pernambucana do Vírus HTLV* (Pernambuco HTLV Virus Association). It operated from 2003 to 2008, referring complaints to the Public Prosecutor's Office and participating in a public hearing in the local state legislative assembly. It pointed out the lack of local services to treat the infection and requested support to adopt measures to structure care for these patients (MPPE, 2008). According to a report by activists from Rio de Janeiro and Bahia, the Pernambuco NGO was unable to continue its activities.

In 2005, in Rio de Janeiro, *Associação de Pacientes "Lutando para Viver"* (Association of Patients "Fighting to Live") incorporated, at the National Institute of Infectious Diseases Evandro Chagas of Fiocruz, the fight for the rights of people

living with HTLV. It was created in 1998 to ensure the rights of all patients undergoing treatment in the unit but due to the greater number of HIV-positive patients, it involved itself in almost exclusively militating for these patients' rights (Andrade; Vaitsman, 2002).

In 2007, the *Grupo Vitamóre* was created, with the support of Pela Vidda-RJ to exclusively claim rights and public policies for individuals living with HTLV. A factor which contributed to the creation of the group was the finding that Brazil only had one association for people living with HTLV, the Pernambuco one. *Grupo Vitamóre* was institutionalized in July 2011 to ensure these individuals' representativeness in governmental agencies. Also in 2011, the Ministry of Health website mentioned the entity as an institution which defended the rights of individuals with HTLV. *Grupo Vitamóre* has an official website, participates in social networks, and belongs to the AIDS/NGO Forum in Rio de Janeiro State to give greater social visibility to the disease. It aims to publicize HTLV as an STI. It advocates serological testing for the virus in prenatal care and its inclusion in the list of compulsory notification diseases (Vitamóre, 2020).

In 2010, *Associação HTLVida* was organized in Bahia to defend human rights, integrate people infected with HTLV, and promote preventive campaigns. It aimed to promote health and establish policies to care for individuals with HTLV in the state of Bahia. It has an official website and a social media page, by which it offers information of the disease, advertises scientific events, and promotes social activities (HTLVida, 2019).

These organizations, as pressure groups, are essential to formulate HTLV-related actions. The next section shows the participation of *Associação HTLVida* to defend the rights of people living with the infection in Bahia.

Associação HTLVida

In September 2010, the *Grupo de Apoio ao Portador do Vírus HTLV* (Support Group for People Living with the HTLV Virus, also called *Associação HTLVida*) was founded to fight for the rights of people infected with the virus in the

municipality of Salvador, Bahia. Dr. Bernardo Galvão, coordinator of Escola Bahiana de Medicina e Saúde Pública HTLV Center, recognized the importance of integrating patients to discuss and plead for public policies, encouraging the organization of the institution (HTLVida, 2019).

In our interviews, militants talked about the difficulties in organizing and maintaining the institution and the strategies they adopted. Currently, it has more than 200 registered individuals, only a small group of which participates in its activities. Interviewees mentioned efforts to maintain a larger cohesive group, indicating some factors regarding the differences in the movement against AIDS: most HTLV-infected people are less economically favored, with low vocalization capacity.

We mobilize Gohn (2013) and its differentiation of NGOs before and after the 1990s, considering that the former demanded changes with little room for dialogue with the State and adopted a coping posture most of the time; whereas the latter constitute propositional institutions in partnership with the State, including service provision. We found that *Associação HTLVida* has a hybrid identity, with characteristics of militant and claimant organizations and of institutions partnering with governmental agencies. The NGO in Bahia, however, acts as a pressure group, accessing various forums (such as the State Department of Health and the Municipal Health Department of Salvador, Health Councils, and the House of Representatives) and develops activities with public agencies.

In addition to acting toward prevention, it seeks to offer a better quality of life for those with the infection; has volunteer professionals in psychology, physical therapy, hypnotherapy, massotherapy, nutrition, integrative community therapy, and legal advice. It assists people in scheduling consultations and exams and refers positive individuals to reference units, according to their demands. It also surveys materials and equipment to donate to patients with disabilities, such as diapers, urethral probes, gloves, wheelchairs, and commode chairs (HTLVida, 2020).

To disseminate information on the infection and aid citizens living with HTLV in Bahia, *Associação HTLVida* seeks partnerships with public and

private colleges, companies, and municipal and state agencies to warn the population about the virus and its forms of transmission and control and distributes information and condoms provided by municipality and state STI managing agencies (HTLVida, 2019).

Kingdon (1984) discusses the dissemination of ideas in policy-making, in which individuals seek different forums to sensitize political communities and society. Moreover, the author claims that disseminating ideas produces a multiplier effect when proposals spread and gain more and more supporters. Regarding HTLV in Bahia, researchers and this organized social movement disseminated ideas, mainly by *Associação HTLVida*, which, by searching for rights in several forums, contributed to promoting the discussion on the theme and the expansion of care in Salvador.

The NGO belongs to the *Fórum de Entidades de Patologias da Bahia* (Forum of Pathologies Entities of Bahia - Fepaba) and the *Fórum Baiano de ONGs* (Bahia NGO Forum - Fobong), which enables it to disseminate the theme in different locations across the state. Fobong initially covered only HIV NGOs, but it included other movements later on. In 2017, the institution was called *Fórum de ONGs e Movimentos de Lutas contra Aids, Hepatites Virais e HTLV* (Forum of NGOs and Movements of Struggles against AIDS, Viral Hepatitis, and HTLV).

Several participants (such as managers, professionals, and activists from other areas) stressed the importance of the movement in defending the rights and expanding actions for people living with HTLV in the municipality of Salvador and its repercussion in the state of Bahia.

I didn't know them before. How important is the role of organized civil society! HTLVida came to us at the beginning of our term. Maybe if they hadn't come looking for us, I wouldn't have become aware of the problem. We have to acknowledge it! (Dr. Helena Cristina Lima, municipal STI program manager; Interview 03; Sep/2018).

How important is the social movement. They [HTLVida] put a lot of pressure on the Municipal Health Department toward a municipal reference for HTLV. Baiana and Hospital das Clínicas were the only ones

before them. Then this doctor has come here with the prospect of also doing the HTLV outpatient clinic. (Coord. Sulamita Prado, basic health unit manager; Interview 06; Sep/2018).

HTLVida, with all their transportation difficulties, are people who really embrace the cause and you understand that they take an interest in working with the disease, with aggravation, with prevention. And, for us, it's good because we aggregate our politics as a State. Civil society and the government need to be together! (Coord. Maria Aparecida Rodrigues, state STI program manager; interview 04; Sep/2018).

The NGO belongs to the HTLV Working Group (HTLV-WG) – coordinated by State Department of Health and including the Municipal Health Department of Salvador management – and discusses proposals to develop actions related to the infection. The educational activities on STIs by the organized movement and public agencies (and their work groups submitting demands, among other activities) are vital to structure a horizontal model of assistance.

HTLVida proposed to make official the municipal day to confront HTLV in the legislative chamber of Salvador. After meeting with activists, Councilman Silvio Humberto drafted a municipal bill in 2016 - approved the following year as Municipal Law No. 9,211 of 2017 - which instituted, in the official calendar of events of the municipality of Salvador, the Municipal Day to Prevent and Combat HTLV, celebrated annually on September 28 (Salvador, 2017). The NGO also won the title of public utility with the promulgation of State Law No. 13,890 of 2018, a qualification necessary for it to claim resources from social assistance, among others (Bahia, 2018).

This research highlights the merit of *HTLVida* regarding the participation of organized civil society in exercising social control and as a pressure instrument for related policies.

HTLVida plays an important role in the exercise of social control and conformation of a public

policy focused on HTLV. As policy coordinator in the state of Bahia, we will not be able to work alone on the issue of political organization, be it HIV, HTLV or other public policies. We need to be with civil society. We need to be with the people who experience the problem first-hand! (Coord. Maria Aparecida Rodrigues, state STI program manager; interview 04; Sep/2018).

Our documentary research found a greater performance of *HTLVida* in the decision-making forums from 2016 onward, with emphasis on health councils and the house of representatives, demanding greater structuring of the care network, the expansion of public policies for infected people, and the reduction of the invisibility of the infection.

Rua (1997) claims that public policies result from a process comprising decisions from public authorities and social participation. In this context, organized movements lead the defense of rights. Civil society associations have the important function of mobilizing and vocalizing the demands of different social groups and exercising social control, guiding themes, and supervising the application of resources and compliance with what has been approved.

The absence of social movements was a factor which impaired the inclusion of HTLV in the Minas Gerais governmental agenda. The lack of organized groups pushing for public policies in decision-making forums prevented the progress of the discussion and the approval of proposals.

HTLVida played an important role in including the theme in the Bahia health agenda. As an entity fighting for the rights of people living with HTLV, it sought opportunities to demand policies, making itself present in different spaces. As a pressure group, as per Kindgon (1984), it promoted discussions on HTLV in decision-making forums and, in turn, together with health sector managers, sensitized parliamentarians and activists from other areas and pushed for the inclusion of the theme, decisively contributing to expanding HTLV actions in the state of Bahia.

Final considerations

In recent decades, organized social movements have become an indispensable actor to conquer social rights. This research showed the important participation of *HTLVida* in demanding public rights and policies for people living with HTLV by promoting discussions on decision-making forums in Bahia and approving and implementing important sectoral achievements.

This study also pointed out that the mobilization of actors organized in social movements favors the introduction of a theme in governmental agendas. Despite its positive experiences, we found that, nationally, people living with HTLV still have a long way to go to organize and mobilize themselves to conquer their rights.

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Authors' contribution

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