Social movement of women with HIV/AIDS: an experience between positive citizen from Rio de Janeiro, Brazil

Abstract  Faced with the historical role of organized civil society in the social responses to AIDS and the global health governance, this paper analyzes the biography of women living with HIV/AIDS, members of the National Movement of Positive Citizens (MNCP), a national network of HIV-positive women. We used a qualitative approach with observations about the actions of the MNCP in Rio de Janeiro and individual interviews with eight members of the MNCP about their motivations and experiences in the movement. Most of the respondents were older than 50 years and had been diagnosed in the 1990s. Their biographies have been marked by social and gender inequalities. Their entry into the MNCP resulted from the need for HIV post-diagnosis support and in health services ill-equipped to receive them. The movement contributed to the reconstruction of social identity, access to information on care and social support. According to the findings, the actions of the movement do not prioritize the feminist movement’s agenda and coping with AIDS-related stigma and HIV vulnerability. Faced with the current global and national context of increased biomedical interventions in AIDS policies and declining resources for the social movement, the study fosters reflections on the challenges of organized civil society in local social responses to the AIDS epidemic.

Key words  HIV/AIDS, Gender, Social movement, Social support
Introduction

Organized civil society has been involved in social responses to the AIDS epidemic following the advent of AIDS in the 1980s. In Brazil, the first organizations involving people living with HIV/AIDS (PLWHA) were determined by intense mobilization in the context of State democratization. This implied placing the issue in a space dispute that did not prioritize macrostructural or minority-related issues, seeking to operate in global health governance. Governance refers here to the patterns of articulation and cooperation between social and political actors and institutional arrangements, which coordinate and regulate transactions that interfere in political-economic systems. To this effect, they use traditional aggregation mechanisms, such as political parties and the articulation of interests, such as informal social networks, in order to provide innovative solutions that, in global governance, apply to transnational challenges, such as the case of AIDS.

Historical waves of social mobilization in the face of HIV are identifiable. From 1985 to 1991, the Brazilian social response was mainly related to the creation of the first non-governmental organizations in the field of AIDS (NGOs/AIDS) which was based on social support and advocacy, political pressure and applied research. During the 1990s, growing transnational activism and the emphasis on the struggle for state care were observed. In the early 2000s, a fragmentation is noted in the work of NGOs, followed by a significant decline of investments in the social movement in 2011. These changes reflect the current global guidelines for AIDS response, adopted by the Brazilian government, focused on expanding the provision of HIV testing and treatment as prevention. Despite the benefits of access to testing and biomedical resources, this approach has been dissociated from investments in necessary actions and the autonomous participation of NGOs to address stigma and conditions of vulnerability to HIV.

The historical performance of the AIDS social movement in Brazil exemplifies how the establishment of social networks in health can contribute to the design, mediation and scope of public policies. The setting of these networks arises from widespread disquiet and discomfort that are aggregated in collective mobilization and assume a social organization with leadership, values, and goals related to the group’s demands.

Faced with due to the relevance of social responses to AIDS and the scarcity of national studies on the experience of members of these movements, this work aims to bring the view of HIV-positive women about their experience in the National Movement of Positive Citizens (MNCP), in Rio de Janeiro. The MNCP is a national network of women living with HIV/AIDS that emerged in the context of the epidemic’s feminization in Brazil, with the purpose of mobilizing, strengthening and integrating HIV-positive women in the national territory.

In 2000, a cooperative and consultative group of women with HIV/AIDS was created in Rio de Janeiro, aiming at the recovery of citizenship, self-esteem, and improvement of the quality of life. In 2004, the MNCP was formalized, with representatives from several states. The network has no headquarters and has not been institutionalized as a social organization; relations are supported by regular meetings and through online communications.

Methodology

This is a qualitative study focused on the relationships, representations, and intentions of human beings, aiming at the discovery of their social codes. The methodological approach was informed by the foundations of symbolic interactionism, whose focus lies in the processes of interaction that occur in social space and the symbolic character of actions. In this perspective, social roles are changeable and adaptable based on the social demand required by the daily activities of social stakeholders that arise from relationships.

The women portrayed here are identified as social actors and protagonists of social scenes. Based on observations of the activities of the MNCP and individual interviews with eight women from the movement, we sought to identify their motivations to be part of the MNCP, the type of action and the meanings assigned by them to the movement.

After the MNCP leadership was made aware of the study, in June 2014, the first author of the paper started to observe the core activities in Rio de Janeiro, at the headquarters of an NGO. During one year, the author had informal conversations and followed MNCP’s activities. Observation became a “participant” as the insertion and permanence in the field favored interaction, the retrieval of data that was not clear-cut, access to documents, and the building of trust ties with women in the network.
Based on the indications of a network leadership and research participants, as well as defined criteria (over 18 years of age, with at least two years of diagnosis and with participation in the MNCP), ten women were invited to participate in the interview, and eight accepted, of which two were founding members of the movement. Considering the meaning criterium of saturation and the observation records, this universe was sufficient to answer the questions of the study. In the interviews, recorded with authorization, topics of social profile, affective-sexual relationship, knowledge about AIDS, care practices, discrimination, social support, pathway in the MNCP and meanings of the social network were addressed.

In data analysis, guided by the Thematic Content Analysis model, we identified the meaning nuclei referring to three thematic axes, namely, gender, care and social movement. In this paper, we prioritized the empirical categories of these axes related to sexual-affective and gender relationships, time of diagnosis, situations of discrimination, social support and participation in the social movement. The research is part of a more extensive study and was approved by the Research Ethics Committee of ENSP/Fiocruz. The names employed are fictitious.

Results

Profile of respondents and sexual-affective relationships

As indicated in the Chart 1, the age of respondents ranged from 38 to 79 years, and with those older than 50 being predominate. Most of them live in the Northern Zone of Rio de Janeiro. Two completed higher education, five completed at least secondary school and one did not complete primary school. Schooling had an impact on the introduction in the labor market throughout their life: the professional occupations (in general with low remuneration) were in administrative duties, sales and education, in establishments or own businesses. At the time of the interview, a significant proportion was receiving the Continuous Cash Benefit and was absent from the labor market, mainly as a result of HIV diagnosis. Only one had paid work in an NGO/AIDS. The reported living conditions indicate that these women belong to the lower income strata.

In the pathways of sexual-affective relationships, all experienced some psychological or physical violence, and the offender was the partner, as well as extramarital affairs, jealousy crises and alcohol abuse by the partner, partly tolerated under the ideal of keeping the family together. In general, among those with lower educational levels, such as Rita and Nara, the normalization of gender oppression was identified by the non-questioning of the partner’s imposition so that they would dedicate themselves to home chores and the care of the children, under the condition that he provided the family with material assets. Among those with higher schooling levels (Betânia, Cassia, and Adriana), we observed that work allowed financial autonomy and favored the rupture of conflicting conjugal relationships. Such a finding reiterates that work can be an instrument in the reoccupation of a social space of women and a source of autonomy and creation of new living standards.

All reported lifelong heterosexual intercourse and, generally, without prevention of sexually transmitted infections due to failure to perceive risk, difficulty in negotiating the use of condoms in steady marital relationships or because it was

<table>
<thead>
<tr>
<th>Name*</th>
<th>Age</th>
<th>Year of diagnosis</th>
<th>Schooling</th>
<th>Occupation</th>
<th>Marital Status</th>
<th>Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adriana</td>
<td>56</td>
<td>1993</td>
<td>IHE</td>
<td>Housewife</td>
<td>Common-Law Marriage</td>
<td>Yes</td>
</tr>
<tr>
<td>Betânia</td>
<td>79</td>
<td>1990</td>
<td>CHE</td>
<td>Housewife</td>
<td>Single</td>
<td>Yes</td>
</tr>
<tr>
<td>Cassia</td>
<td>38</td>
<td>1994</td>
<td>CHE</td>
<td>NGO Activist</td>
<td>Married</td>
<td>Yes</td>
</tr>
<tr>
<td>Elza</td>
<td>47</td>
<td>1993</td>
<td>IHE</td>
<td>Housewife</td>
<td>Married</td>
<td>Yes</td>
</tr>
<tr>
<td>Marisa</td>
<td>40</td>
<td>2013</td>
<td>CSS</td>
<td>Housewife</td>
<td>Single</td>
<td>Yes</td>
</tr>
<tr>
<td>Nara</td>
<td>50</td>
<td>1995</td>
<td>IPS</td>
<td>Housewife</td>
<td>Single</td>
<td>No</td>
</tr>
<tr>
<td>Roberta</td>
<td>56</td>
<td>1999</td>
<td>CSS</td>
<td>Housewife</td>
<td>Single</td>
<td>Yes</td>
</tr>
<tr>
<td>Rita</td>
<td>56</td>
<td>1999</td>
<td>CSS</td>
<td>Housewife</td>
<td>Single</td>
<td>Yes</td>
</tr>
</tbody>
</table>

an unusual practice at the time. HIV infection resulted primarily from unprotected sex with their husbands (now deceased due to AIDS) or unstable partners. Two attributes the infection to blood transfusion, one of them in an episode of clandestine abortion. The context of HIV discovery, predominantly occurring in the 1990s, was due to own or partner’s illness, in prenatal care and a blood donation screening; only Rita discovered it in the context of routine health assessment.

After the diagnosis, three returned to have sexual-affective relationships and revealed their diagnosis to their partners. The option for solitude and sexual abstinence reported by the others (single at the time of the interview) was primarily associated with HIV and corroborates evidence from the literature. Today, they have a clearer picture of the exercise of sexual and reproductive rights, but they still affirm some limitations in the management of sexual-affective relationships and reinfection risks. For example, although they report having no condom access restrictions, they are not always able to convince their partners to use them.

From HIV diagnosis to joining the MNCP

Until they were diagnosed, all the respondents perceived themselves as almost immune to AIDS because they did not engage in what they considered deviant practices (gay relationships, prostitution, and drug use), which are still associated with the epidemic. They were surprised by the HIV diagnosis. According to their account, after confirming that they were infected, they did not receive support, listening or focus on the conditions of vulnerability to AIDS. It should be noted that post-diagnosis advice is part of the national guidelines, but its implementation remains a challenge.29

Faced with the non-reception by the health service and the fear of the discovery of HIV-positive status, respondents sought support from family members (partners, mothers, grandmothers, sisters), religious organizations and the social movement of PLWHA (not necessarily the MNCP). Previous experiences motivated the search for the social movement in collective spaces (student movement, NGOs, interactive groups in other health services) and contacts with activists in these contexts. Elza's statement illustrates the demand for peer interaction and the exchange of experiences:

So I needed to know what I had, and I needed friends who had the same thing as me, to feel welcomed, because I was alone, my partner would not let me talk about it. [...] I lacked information, ... how were people living, what were they doing? (Elza)

Similar support has occurred in HIV-related discrimination situations. Marisa went to an NGO and was warmly welcomed when her privacy had been violated whilst in the care of the Family Clinic. Elza had her wall repainted by the NGO after “the home of AIDS” had been graffitied onto her home, when she participated in a media prevention campaign in the 1990s.

In addition to the social support of the movement, the entry into the organization favored the encounter and interaction with people sharing a common situation (HIV), producing reflections on the reconstruction of their social identities—post-diagnosis22 and the change of social roles from this new condition. The invitations to participate in research and media reports experienced by all illustrate how belonging to the movement can demand and favor the exercise of a constructed identity of the HIV-positive activist. Elza's statement reveals: “I cease to be an anonymous housewife and become a reference [...] I can contribute.”

Although an HIV-positive woman identity has been constructed, today, most do not assume their HIV-positive condition publicly. Due to the fear of the AIDS stigma, silence or selective revelation prevails. It should be noted that the dilemmas and fears of the disclosure of diagnosis were not addressed in the observed conversation groups of the MNCP. According to the respondents, there is no stimulus or action by the movement focused on coping with the HIV stigma. While present in the charter of MNCP’s principles, the theme has not been debated.

Activities and meanings associated to the movement

The permanence in the MNCP was defined by the secure bond and by the meanings assigned to the space. Some introduce themselves as “militant” or “activist”, such as Cassia, Elza, and Betânia, with a leading role in the movement. Despite the different uses and attributes, the terms “activist” and “militant” are used synonymously here, given the similar form in the respondents’ statements. Rita has been participating for a shorter time and affirms her interest in the organization’s political activities and the struggle for the rights of HIV-positive women, recently assuming the role of deputy among the leadership.
On the other hand, Roberta is attending meetings to obtain information and would rather not share her experiences. We also have “transient participants”, such as Adriana and Nara, whose interest is the expanded social networking and interaction between peers, within and outside the MNCP, “to once again meet some people that you sometimes lose along the way. Moreover, the hope of suddenly [laughing] finding someone, [...] and that becoming a relationship” (Adriana). Both are irregular visitors to this space.

Despite the varying types of involvement of the respondents with the MNCP, interaction with other female PLWHAs intensifies the exchange of experience and the establishment of a social support network. Few, however, engage in political activism. During the study period, it was noted that respondents rarely participated in the mobilization spaces promoted by the MNCP, in partnership with other social movements, such as: regional seminars of the movement, Working Group on the Feminization of STIs in Rio de Janeiro (composed by representatives of the Municipal Health and Education Secretariats, the Special Secretariat for Women’s Policies of DST/AIDS Management and other HIV/AIDS NGOs) and Public Hearing on sexual and reproductive rights of HIV-positive women in the Legislative Assembly of Rio de Janeiro.

For the respondents, one aspect that compromises the greater participation in the movement concerns the adverse effects to their self-care, due to the occupations assumed. Roberta’s statement illustrates: “One of the reasons that also made me stop was that. Go here, go there, travel here, and so forth. It’s exhausting.” In this context, we note an overload due to the assumed role in the dynamics of care of others and undertaking domestic chores, from a perspective of normalization of care as female work. HIV emerges as a “new condition”, which implies reconciling care of others and self-care, and participation in the movement.

Another factor that may interfere with women’s relationship with the movement is the mobilization capacity of the social movement itself. The fact that the MNCP cannot attract a significant number of women and work overload among the few members, as attested by some leaders, stimulates a questioning about its objectives and strategies of action. During fieldwork, it was observed that the discussion topics in the conversation groups were pre-defined in an annual agenda and counted with the participation of “expert” guests. However, the conversation group was much of the time about sharing participants’ life stories, which compromised and limited the time of debate on political issues and issues on PLWHA’s rights and care.

This analysis must consider the situation of health policies and the participation of organizations in civil society in the country. As mentioned in the introduction, this last decade was marked by lower financial support to the projects of the NGOs, as well as by the loss of protagonism of the social movement in the formulation of policies and social control. Spaces that previously ensured the social mobilization of agendas related to PLWHA’s dissatisfaction, nowadays have difficulties in developing and are unable to absorb the demands of social support and reception in collective living situations. Elza evaluates the current situation of the movement:

Positive Citizens is an interesting movement; it is somewhat weakened by the constraints of current affairs. [...] AIDS becomes a chronic disease, and nobody cares about it anymore, and women do not care either. (Elza)

Other respondents shared the vision of the weakened movement. However, there is a consensus that after the diagnosis, the movement has played the role of social support in their lives, allowing a new way of addressing with the “new” personal interactive reality with the virus. They believe that this space still holds that potential.

Because she [the woman] is empowered. She has the information; I believe this even helps her look differently. I believe this, in itself, differentiates the woman without any information from a woman who is in the movement and is empowered, knows what she wants, what she seeks, what she fights against, she has goals, she has her objective... (Cassia)

Some suggest that participation in collective spaces (and not specifically in MNCP) positively interferes with the way they address care, the possibility of educating themselves, exchanging information and strengthening self-care. The political character of the movement, aimed at the struggle for rights and confronting stigma, could be more present in this set of contributions to care, but it does not appear. In the conversation groups, the few reports of dissatisfaction with care, which triggered individual movements for improvement, illustrate the lack of emphasis on the social mobilization of the organization.

**Feminine, but not feminist**

Based on the observations of the MNCP’s activities and statements, we can observe that the
movement, while feminine, is not feminist. The agendas on the implications of gender norms and the struggle for women’s social, sexual and reproductive rights are poorly addressed. Reflections on established power relationships, body control, and contexts of social and gender inequalities in everyday life are scarce. MNCP’s work in Rio de Janeiro now seems to focus more directly on the debate on the assurance of specific assistance and care to HIV-positive women, which still does not ensure the materialization of active participation in the construction of public policies, as already described.

According to some respondents, a more “preventive” character prevails in the movement, with prioritized agendas such as assisted reproduction, prevention of elective cesarean section, assurance of continuous milk formula for children of HIV-positive women and supply of and encouragement to use condoms and other contraceptive methods by public health services. Feminist agendas, such as the discussion of decriminalization and legalization of abortion, did not appear on the monthly conversation groups, and violence against women was discussed very rarely. When the theme arose, the focus was mostly on the provision of post-exposure therapy to victims of violence. Nevertheless, both themes (abortion and violence experiences) were present in the respondents’ life journeys. When debated, body realms were restricted to the effects of lipodystrophy and the need to fight for free surgical correction. Job security, in the context of HIV/AIDS, was not brought to the conversation groups, although it was debated in the statements and referred to as an agenda in the official document of the regional meeting of the movement in 2014.

Discussion

The pathway of the respondents reiterates that social and gender inequalities, coupled with the stigma of AIDS, increase women’s vulnerability to HIV by limiting the exercise of their capacity for agency and the transformation of reality. Despite the generational contour, since most of the respondents were infected in the 1990s, recent studies reveal few changes in the contexts of women’s vulnerability to HIV.

Faced with the surprise and fears of HIV diagnosis, not all respondents found the reception they expected in health services, indicating the absence of or limited advisory actions, as well as the lack of provision of groups in the health services. As advocated, counseling has the potential to favor active listening between user and professional, in the same way that services can foster dialogue among users about expectations and anxieties of the future, building relationships and developing autonomy, from meetings in the services.

In search of other social supports after the diagnosis, besides some of their relatives, the respondents turned to social movements, such as the MNCP. Valla defines social support as a shared device that seeks to meet the (emotional, financial, for example) needs of people who join groups in associations, clubs, church, and so forth. The author argues that this demand arises, among other reasons, from limitations of the State in assuring the provision of quality services and well-being.

According to reports, involvement with organizations (not exclusively MNCP) seems to be an essential part of the process of reconstructing post-diagnostic identities and re-articulating relationships, creating new social networks. The social networks in health are a form of collective action, the result of a broader social process, whose action advocates common interests, types of support and can identify new political practices. This reiterates that participation in PLWHA groups plays a relevant role in sharing and managing life with HIV/AIDS, including access to information on treatment and the role of the social network.

However, the analyses suggest that the movement hardly addresses the basic aspects associated with social vulnerabilities, both before and after HIV, such as social and gender inequalities. Historically, this perspective has characterized the non-governmental response to AIDS. The female body and its autonomy, for example, are discussed only when the debate is directed toward modifications secondary to treatments, disease, and consequences for personal relationships. Thus, the nature of common practices in the context of a women’s movement dissociated from the feminist movement seems to hinder the establishment and expansion of social networks with other movements and the questioning of the structural realm. As Stotz argues, the construction of common agendas in these networks and collective decision-making characterize the establishment of alliances and possible social change.

The lack of feminist guidelines in the MNCP can be understood, in part, by the historical re-
sistance to the inclusion of HIV in the feminist movement. According to Barbosa\textsuperscript{35}, the difficulty of the rapprochement and partnership between the movements of HIV-positive women and feminist movements has resulted in the absence of relevant themes of feminism in the debates of the HIV/AIDS movement. Besides, there has been little elaboration by feminists on the social issues that traverse the epidemic. Based on the social movement of women with HIV/AIDS in Mexico, Amuchástegui\textsuperscript{36} advances in this discussion by pointing out that, unlike gay groups, which were already politically organized before AIDS, most infected women were not part of social movements. After HIV diagnosis, some were included in mixed NGOs (which were the majority) and not in women’s organizations.

Given the focus on a social movement of HIV-positive women, it should be noted that women’s vulnerability to HIV has gained visibility through increased HIV/AIDS cases among women in the 1990s; followed by a certain stabilization of the growth of cases after 2000. In this context, the operationalization of governance has developed into public AIDS policies geared to the female public, such as the Integrated Plan to Combat the Feminization of the AIDS Epidemic and other STDs\textsuperscript{37} launched in 2007.

In assessing this Plan\textsuperscript{38}, achievements were identified, such as establishing partnerships, strengthening some NGOs, integrating with government agencies that work with women, and sensitizing managers. However, there has been little progress in addressing social and gender inequalities associated with the vulnerability of this population to HIV and the situations of physical and sexual violence found in the daily lives of several women\textsuperscript{39}. The plan’s discontinuity has compromised the scope of its actions. Currently, the programmatic actions of AIDS for women are focused on the prevention of vertical transmission of HIV, based on the policy of prenatal care and childbirth screening\textsuperscript{39}. It is important to highlight the lack of government programs aimed at the sexual and reproductive rights of PLWHA and HIV prevention actions for women outside the pregnancy period.

Regarding the fight against AIDS stigma, it should be pointed out that, although they are members of a social movement, most respondents affirm that they do not currently reveal HIV diagnosis. The concealment of diagnosis stems mainly from the fear of situations of discrimination, violence and social marginalization, which shows the tensions still present between the private sphere (not revealing the diagnosis of HIV to avoid discrimination and violence) and the public sphere (importance of HIV visibility to cope with stigma, despite the right to secrecy)\textsuperscript{32}. Despite their relevance, the origin and persistence of HIV-related stigma and the means to deal with it have not been addressed in the discussions and actions under the MNCP.

In the sociological studies of stigma, Goffman\textsuperscript{32} points out that concerning this ‘group-of-equals’ (the stigmatized), one can discuss the natural history and respectable career of the stigmatized individual. However, if the aspect is not addressed, the experiences and the means to tackle it are no longer shared. It’s not by chance that most respondents do not perceive in this scenario a space for the deconstruction of stigma.

Another point refers to the barriers that the MNCP has found in the articulation of two fundamental aspects: the action in the political sphere and the social support to the PLWHA. Some respondents recognize the importance of MNCP’s political action in the fight for rights and improvements in the care of PLWHA. However, active participation is reduced to a few members, generating an overload for a minority group.

According to reports, one of the limitations of expanding participation in the movement is the difficulty in reconciling the activism tasks with domestic activities and care for others (grandparents, parents, children, husbands, grandchildren). Such functions are found in the daily life of the respondents before and after HIV diagnosis and tend to be socially perceived as a labor activity. It should be noted that these situations, associated with gender inequalities, were not discussed in the conversation groups or other actions of the MNCP. This gap reveals a possible aspect to be explored as a strategy of the movement, as other studies with HIV-positive women indicate\textsuperscript{35}.

Based on the findings, it appears that MNCP does not seem to stimulate activism among women, although several of them have previous experience of participation. There seems to be little investment of the movement in the proposal of facing the conditions of social vulnerability that traverse the daily life of women. One respondent suggested that the organization promote increased listening to the problems and conflicts experienced by HIV-positive women. From
this understanding, concrete actions capable of transforming different sectors of people’s lives, including the formulation of policies could be defined. As pointed out, the current State programmatic actions have prioritized access to testing and treatment, especially in prenatal care.

The performance of non-governmental responses to the AIDS epidemic, especially in the second decade of the 21st century, reveals limitations and no longer has the same capacity to operate in health governance at national and global levels as at other historical moments. The difficulties of maintaining NGOs are evident, given the lack of resources and the reduced value of their role in the social control and the formulation of policies. Today, in Brazil, it has not been uncommon for NGOs/AIDS to provide services related to the demands of government policies, such as expanding testing for treatment and prevention. Such a situation is a cause for concern since civil society is empowered by the debate and the tensions it fosters, which can add themes and perspectives that probably might not be considered on the national or global agenda.

Finally, it is worth noting that, given the lack of a seat of the movement, the exchange of information and maintenance of support among the members of the MNCP is supported mostly by a virtual social network, and less by face-to-face meetings. A virtual social network is a contemporary tool with a unique potentiality. According to Machado, this resource is vital for the organization and articulation of communities, as in the setting of new social movements and activism. Perhaps this technology is not being used to its full potential by MNCP, but this aspect would have to be better explored in future studies.

Final considerations

The results of the study reiterate some of the current challenges of the social movement of AIDS in its historical role of coping with conditions of vulnerability to HIV, social control and the fight for rights and quality of PLWHA care. Despite limitations of the study – associated with the population, generational and regional contour, the number of interviews and the further analysis of other aspects of the biographical pathway – the analysis suggests that it is appropriate that the MNCP reflect on its strategies of action from a macro-structural political perspective. In the field of increased struggles of “collective” social actors, it may make more sense to seek the unification of network struggles. It is crucial to recognize their particular agendas, but also to appreciate the community’s experience of a general context of denial of rights.

In short, it is necessary to look for alternatives in the face of fragmented and weakened social movements in the field of AIDS, aiming to recover their role in developing responses to the challenges of the epidemic in the country. Spaces of political activism favor the development of actions to address psychosocial suffering, understand collective oppression and mobilize citizenship toward what supports personal reinvention and intersubjective contexts. This rationale of reconstructing one’s identity and the interpersonal relationship will help reduce vulnerability to morbimortality. They are spaces that invite the expanded consciousness toward collective emancipation and the so-called psychosocial emancipation. There is an essential role of mutual help, but also of clarification on fundamental rights and reconstruction of scenarios of ruptures due to AIDS.

Faced with the current context of greater biomedical interventions in AIDS policies and shrinking resources for the social movement, this study fosters reflections on the challenges of organized civil society in local social responses to the epidemic. Among them, the relevance of rethinking how to transform practices regarding social support and political participation, social movements, and healthcare devices. Such proposals’ central axis should be the understanding of the processes of social and gender inequalities that traverse the pathways of social stakeholders.
Collaborations

LCS Staff was responsible for the development of the study, data analysis and article writing. S Monteiro participated in the design of the study, methodological orientation, review of data analysis and article writing.

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