

# HIV/AIDS care policies and practices: interdisciplinary dialogues

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DOI: 10.1590/0103-11042022E7001

**THE PUBLICATION WE HAVE IN OUR HANDS RESULTED** from the meeting of a group of researchers and health professionals from various teaching and research institutions with the objective of knowing, gathering, and making visible academic research and analysis of experiences on HIV/AIDS care in the current context.

As a field of knowledge and practices<sup>1</sup>, organized by the Associação Brasileira de Saúde Coletiva (ABRASCO) in three areas – social sciences and humanities in health, planning, and epidemiology –, collective health is in permanent construction over time, choosing as themes from aspects linked to policies, work organization and health systems, to micropolitics and people’s everyday experience. Therefore, side by side with the production of data and systematic surveys, the biographical aspects of the various interlocutors (whether they are researchers, professionals, and/or research participants, in interaction) have also been relevant to configure and reconfigure the perspectives on such topics. Initially, therefore, this group of editors, crossed by epistemological and disciplinary diversity and constant dialogue, represents the meeting of many voices and backgrounds, as well as the willingness to renew and challenge itself, in constant action, just like the field of collective health itself.

As Ruben Mattos<sup>2</sup> – to whom we dedicate this thematic issue – taught us so well – in what would become one of his best-known texts (“The senses of integrality”), the confrontation of HIV/AIDS was initially configured as a policy designed to respond to the needs of specific groups, integrating prevention and care actions. As the late professor wrote, “the Brazilian government response to AIDS has always been guided by respect for the rights of those who live with this disease” and “encompassed a wide range of strategies and interventions”, including “the various groups affected by the problem, respecting their specificities”<sup>2(65)</sup>.

Many years after having written this text, Ruben was with us at the seminar on the care for People Living with HIV/AIDS (PLWHA) in the health care network, held in Rio de Janeiro in February 2020, and drew attention to the crisis that began with the removal of President Dilma Rousseff from the Presidency of the Republic of Brazil, underlining the fact that the Social State has become, under the Temer administration (onwards, we would add), “an expenditure problem”, with Constitutional Amendment No. 95, the “CA of the public spending cap”. From then on, as he stressed in his speech, “social expenditures that were thought of from a constitutional rights

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*perspective became expenses in general*". Ruben was there problematizing the relationship between resources (of all kinds), rights, and care. In this way, he taught:

[...] care is not a product of the health service to be managed. It is a set of social practices that go far beyond health services or health professionals.

As was his style, in what was one of his last public speeches on HIV/AIDS, he called on everyone to fight against setbacks and threats to rights, valuing militancy and the invention of possible forms of resistance despite the unfavorable and conservative conjuncture at the time<sup>3</sup>. Soon after this seminar, the world watched and was swallowed by the COVID-19 pandemic – us included. Thus, in the midst of so many losses, Ruben passed away; however, he left us a work as extensive and dense as his capacity to instigate. His life is still a source of inspiration for several generations of researchers, professionals, and activists in the field of HIV/AIDS, and certainly among those who came here to contribute to this issue.

In 40 years of the AIDS epidemic, the social impact of the epidemic in the first decades was a central guideline for AIDS policy in the country, which became known as 'the Brazilian response to HIV/AIDS'. Today, vulnerabilities still experienced by PLWHA, such as stigma, discrimination, inequity and social exclusion, continue to be challenges to their care, hindering access to care and compromising its quality.

Considering the equity of the health system, understanding and meeting the needs of subjects and social groups, and building care practices capable of opposing the processes of vulnerability experienced, require us to analyze the characteristics of the epidemic, the policies and health care offered, and the setbacks in achievements in the response to the HIV/AIDS epidemic, understood as the emphasis on biomedicalization and the abandonment of the perspective of human rights<sup>4</sup>. It is also important to include in the debate the impact of the intensification of inequalities in the distribution of new cases around the world, the implications of the resurgence of conservatism, authoritarianism, deadly political affections, and the intensification of neoliberalism in the face of its own crises. To this scenario, we can also add the several impacts from the pandemic of the COVID-19, which, in the years 2020 and 2021, were felt in all areas involving HIV/AIDS care, from the decrease in the demand for diagnostic tests to the greater spacing of consultations and the difficulty of access to care by PLWHA. Although these are problems that cross the entire country, the singularities of each regional and local context also acquire relevance in the way the AIDS epidemic takes shape and is faced in the various territories.

In order to reflect more deeply on the complexities of the current context, we proposed this thematic issue, which has as its main motto the reflection and dissemination of studies on care policies and practices from an interdisciplinary perspective. However, just like integrality, care is also a polysemic term<sup>5</sup>, and it is an object of attention not only in the field of collective health, but also in several other fields of knowledge, such as psychology, nursing, philosophy, and the social sciences<sup>6</sup>. When we talk about care, we can look at health systems and services, observing how the relationships among the various subjects in the practice of health care (managers, professionals, users) occur in their different levels, or we can include support networks and the daily organization of care within families, neighborhoods, communities, and movements. When it comes to HIV/AIDS, talking about care implies taking into consideration the historical record, the importance of solidarity and welcoming within the most affected communities at the beginning of the pandemic, and the current moment in which chronicity imposes new

challenges for individual and collective management of the infection, while changes in the field of prevention open differentiated possibilities and challenges for different social groups. It is also about the importance of the hidden work and its gender dimension, the affections and moralities involved in the care relationships, as well as its emancipatory possibilities<sup>7</sup>. Based on this interdisciplinary – as well as intersectional, intergenerational, and intersectoral – approach, we thought of a set of questions that we hoped to address through the publication of this issue:

What is care in HIV/AIDS? In what spaces is care produced? Which actors are part of this construct? How has HIV/AIDS care been produced in different Brazilian contexts? How does it relate to people's access to health networks and services? What social markers and axes of analysis are important in an analysis of care in HIV/AIDS? (Gender? Sexual identity and orientation? Class? Color/race/ethnicity? Religion? Age? Body? Sexuality? Technology? Management? Work processes? Others?) What/how do policies entail HIV/AIDS care? How do the experiences of people/subjects/individuals/users/patients articulate themselves in these threads?

## About the thematic issue

The set of articles presented here is representative of the diversity of perspectives and approaches on care in HIV/AIDS in the field of collective health and from different contexts – academia, management and social movement.

The first two texts of the Original Articles section of this thematic issue discuss the decentralization of care in HIV/AIDS. 'Interface between primary and specialized care in a context of decentralization of services for HIV/AIDS', by Fatima Rocha, Eduardo Melo, Rafael Agostini, Ana Carolina Maia and Ivia Maksud, discusses the interface between Primary Health Care (PHC) and specialized care. The authors show that it has taken place more in a binary and isolation logic than in a perspective of interaction and (shared) management of care, which would be expected in a care network conformation. Despite the potential gains in access and 'rationalization' of the use of specialists (infectologists), the researchers indicate the need to strengthen processes and mechanisms of communication and interaction among professionals from different types of services, as well as devices for care coordination, such as matrix support and network-integrated electronic medical records. Then, in a more evaluative perspective, Bernardo Lago Alves, Regina Ferro do Lago and Elyne Montenegro Engstrom evaluate the degree of implementation of a broad, recent and heterogeneous experience of care to PLHA in PHC, contemplating structural, technical and organizational aspects, in the text 'Care for People Living With HIV/AIDS in Primary Health Care in the city of Rio de Janeiro: an implementation evaluation'.

Thinking about the theme of care with emphasis on vulnerable populations, the article 'AIDS and prevention: a retrospective view at social projects with young people in Rio de Janeiro', by Vanessa do Nascimento Fonseca, Marcos Nascimento and Simone Monteiro, is configured as a socio-anthropological study of two projects developed in the Maré slum in the decade of 2000. The rescue of the memory of the social interventions highlights the experiences of sociocultural approach on sexuality developed and that contrast with the setbacks evidenced in the policies of sexual and reproductive rights in the last two decades. The emancipatory character present in the sharing of these experiences brings vigor and learning to respond to the challenges present in the field of vulnerabilities.

Similarly, the article ‘Sexuality, sociability, work, and HIV prevention among vulnerable populations during the COVID-19 pandemic’, authored by Carla Rocha Pereira, Marly Marques da Cruz, and Vanda Lúcia Costa, addresses the impact of COVID-19 on the access of Men who have Sex with Men (MSM) and transgender women to HIV prevention technologies in Curitiba/PR. The data discussed in the article comes from qualitative research with semi-structured virtual interviews and also addresses issues related to sexual practices, sociability and work in the pandemic context.

‘The suffering of women living with HIV and inner love as a revolutionary practice’, by Eliane Oliveira de Andrade Paquiela, Eluana Borges Leitão de Figueiredo, Marcela Pimenta Guimarães Muniz and Ana Lúcia Abrahão, discusses the effects of stigma associated with HIV, using Federici’s loneliness and bell hooks’ inner love as categories of analysis. The analysis of the narratives of a group of women allows us to reflect on the need for care by health professionals and to consider listening to the suffering experienced by them. In the sequence, the article ‘Leather on leather’: men with homosexual practices and HIV prevention in the Recife Metropolitan Region’, written by Luís Felipe Rios, Karla Galvão Adrião, Amanda Albuquerque and Amanda França Pereira, addresses the sexual practices and HIV prevention in MSM circuits in the Metropolitan Region of Recife. With a quanti-qualitative methodology, the article gives visibility to regimes of pleasure dissident from heterosexuality and presents paths for possible preventive actions that incorporate these practices and their meanings for the researched group. Although the research was conducted in a combined pre-prevention period (in 2016 and 2017), the results dialogue with the current context of the epidemic and bring up issues often hidden in hegemonic discourses linked to prevention.

The article ‘Travesti sisterhood is our cure’: sisterhood among travestis e and transgender women in accessing health care and HIV prevention’, by Aureliano Lopes da Silva Júnior, Mauro Brigeiro and Simone Monteiro, discusses the strategies for access to public health services and HIV prevention developed by transvestites and trans women in the metropolitan region of Rio de Janeiro. The article emphasizes the responses generated by the group in the face of imposed human rights violations and presents us the agency of transvestites and trans women as a way to face the barriers of access to health care, building a strong network of solidarity – sisterhood – in which mediates the relationship with the territory, health devices and experience with HIV/AIDS.

The generational discussion stands out in the texts from different perspectives. Aiming to contribute to the understanding of new forms of activism in HIV/AIDS that emerged in the decade of 2010 in Brazil and its relationship with processes of subjectivation and construction of informal care networks, Pisci Bruja Garcia de Oliveira and Júlio Assis Simões analyze, in the text ‘Sexual politics and HIV/AIDS activism: the experience of Loka de Efavirenz’, how participants of this collective (female) perceive, experience and face the effects of HIV/AIDS in their daily lives. The analysis unveils the intertwining of stigma with the social markers of gender, race and class. In the sequence, the article ‘Young women born with HIV: communication of seropositivity to partners’ gathered the researchers Clarissa Bohrer da Silva, Maria da Graça Corso da Motta, Renata Bellenzani, Crhis Netto de Brum, and Aline Cammarano Ribeiro, who, from an analysis based on the vulnerability and human rights frameworks, discuss the communication of the HIV status to partners and claim for care and support practices in intersubjective and structural contexts. Finally, the authors of the article ‘Frontline health professionals’ perceptions about HIV and youth’ – Maria Izabel Sanches Costa, Gabriela Lotta, Juliana Rocha Miranda, Laura Cavalcanti Salatino, Elisabete Agrela, Maria Cristina Franceschini, and Marco Akerman – aim to understand how professionals from specialized and primary care operate with categories of

risk behavior and youth in an institutional context of ambiguity in protocols and problematize if such perceptions are in line with public policies.

The biomedical technologies appear in two articles that address 'sexual PEP' as a care strategy, allowing us to contrast the strategy in different regions. In 'If you drink, do not have sex': questioning the discourses in the offer of Post-Exposure Prophylaxis (PEP)', Willian Nathanael Cartelli de Paula and Gustavo Zambenedetti problematize the power relations from the discourses and knowledge of health professionals who work with the effectiveness of sexual PEP in a medium-sized city in the central region of Paraná, concluding the importance of qualifying access to sexual PEP and affirming it as a practice of freedom. Sandra Filgueiras, in turn, in 'Post-sexual Exposure Prophylaxis in the Unified Health System: possible cares in HIV prevention', analyzes, in the light of integrality, the ways of applying sexual PEP in a public health service, reflecting on challenges to be faced, so that the search for prophylaxis is a care device, which ensures access to preventive technologies, from informed choices, according to the needs of people at different times and contexts of their lives.

Finalizing the articles section, the care for people with HIV/AIDS deprived of freedom is the highlight of the text 'Construction and validation of an instrument to assess the care for prisoners living with HIV/AIDS', by Fernando Henrique Apolinario, Silvia Justina Papini, and Wilza Carla Spiri. This is a methodological development study with the objective of building and validating indicators for health care, based on five dimensions: Physical Structure; Human Resources; Work Process Organization; Health Records; and Treatment Adherence.

The thematic issue is also composed by five essays that dialogue in a strong way with (varied) concepts of care. In 'Vulnerability, Care, and integrality: conceptual reconstructions and current challenges for HIV/AIDS care policies and practices', José Ricardo Ayres analyzes the challenges of the response to AIDS in the current sociopolitical scenario, mapping logics and technologies in dispute (including in the field of prevention), as well as conceptual reconstructions necessary for the new moment. In a convergent way, 'Remaking HIV prevention in the 5th decade of the epidemic: lessons from the social history of AIDS', written by Gabriela Junqueira Calazans, Richard Parker and Veriano Terto Jr., analyzes the challenges and responses to AIDS in its 40 years. From the history in the field of prevention, the authors suggest priorities for prevention in the coming 5th decade, present ethical-political principles that were the basis for successful responses to AIDS in Brazil, pointing ways to, as they wrote, 'reimagine prevention'. Focusing on old challenges, 'Biopolitical government of AIDS: the homosexuality as a social dangerousness', Luiz Barp, Myriam Mitjavila, and Diego Diz Ferreira reconstruct homosexuality in light of the notion of biopolitics (precisely the management of sexuality), problematizing the representation of danger (linked to sexual practices) that is attributed to it as well as possible updates in current care devices.

The biographical perspective can be seen strongly in the final essays. 'Memory and experience with children and young people living with HIV/AIDS: an autoethnographic essay', authored by Mariana de Queiroz Rocha Darmont and Martha Cistina Nunes Moreira, proposes autoethnography as a method in dialogue with the anthropology of emotions, allowing the authors to revisit the field of care, relationships and practice in a critical and reflective perspective. In turn, 'An essay on the chronicity of living with HIV/AIDS in childhood, adolescence, and youth' collects reflections resulting from two decades of research and performance in the field of HIV/AIDS by three authors: Claudia Cunha, Marcelo Maciel and Martha Cistina Nunes Moreira. Based on the notions of experience, memory, and disturbance, the essay discusses the chronicity of living with HIV/AIDS for children, adolescents, and youth, with attention to the vulnerabilities and limitations in the circulation and affections of daily life.

The thematic issue also brings an Experience Report written by Daniele Souza, Carla Pereira, and Juan Raxach, who present the book ‘What if it was with you? Lived Stories of Stigma and Discrimination in 40 Years of HIV/AIDS’, a publication of Brazilian Interdisciplinary AIDS Association (ABIA) that brings together moving accounts, in short story form, of ten subjects directly affected by HIV/AIDS. Its intention is to stimulate solidarity with this group, addressing the challenges of moral judgment, transphobia, LGBTQIA+ violence, empowerment, among others, but also bringing stories of reinvention of life itself.

We end this thematic issue with the interview ‘HIV/AIDS Policies, Activism, and Anthropology: A talk with Richard Parker’, in which participated, besides the interviewee, Mónica Franch, Luziana Silva, Geissy Reis, Marcos Carvalho and Vagner Almeida. Richard Parker is an anthropologist and activist who is one of the central actors in the Brazilian response to the HIV/AIDS epidemic. In the interview, the interviewee talks about his trajectory as an anthropologist and his approach to the theme of AIDS, as an activist and researcher. In parallel, he reflects on the 40 years of the epidemic, emphasizing the achievements and challenges in its confrontation and denouncing the accelerated dismantling suffered by policies and services aimed at HIV and AIDS in recent years. The reflection on the lessons learned along this path inspires us and calls us to produce new forms of resistance.

This thematic issue celebrates the maintenance of the agenda of studies and interventions on the theme of HIV/AIDS in a conjuncture that was very unfavorable to it. We hope that this publication contributes as another inspiring instrument for the care practices of PLHA, as well as for the policies that support them in the perspective of equity, health promotion and defense of life, in a scenario of resumption of a more democratic life in the face of setbacks and violation in recent times. It is appropriate to register that we started the production of this thematic issue in a moment of threat to democracy and science, and that this project, with all the developments it has had, including the production of this collection, has fed us and contributed to our daily resistances for many times. We finalize the process after the presidential elections that elected Luiz Inácio Lula da Silva President of the Republic, and in this current conjuncture we place hope and expectations for more investments in the health area, in the resumption of the participation of organized civil society, in the resources for universities, in the production of knowledge driven to the reconstruction and resumption of the sanitary reform project. To publish it in the journal of the Brazilian Center for Health Studies (CEBES) is, for us, a reason for immense joy.

## Acknowledgements

The production process of this thematic issue involved not only editors and authors but also a large group of invited referees who contributed with opinions that subsidized the selection of texts presented here. We would also like to thank Katia Ovídia José de Souza who collaborated in assisting the editors.

## Financing

Research Incentive Project – PIP III – of the Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira, Fundação Oswaldo Cruz, within the scope of the project O ‘cuidado’ às PVHA na rede de atenção à saúde (Care for PLWHA in the health care network), coordinated by Ivya Maksud and Eduardo Melo.

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