At the intersection of two pandemics: the experience of social support networks for youth and adults living with HIV/AIDS during the Covid-19 pandemic

Claudia Carneiro da Cunha[1] (ORCID: 0000-0002-2338-6386) (cunha.claudia@gmail.com)
Luciane Stochero[2] (ORCID: 0000-0003-0432-2739) (luciane.stochero@gmail.com)
Leonardo Aprígio de Almeida[1] (ORCID: 0000-0001-9901-4215) (aprigio.psicologia@outlook.com)
Aureliano Lopes da Silva Junior[3] (ORCID: 0000-0002-9872-9830) (aurelianolopes@gmail.com)
Washington Leite Junger[1] (ORCID: 0000-0002-6394-6587) (wjunger@ims.uerj.br)

[1] Universidade do Estado do Rio de Janeiro. Rio de Janeiro-RJ, Brazil.
[2] Escola Nacional de Saúde Pública Sergio Arouca, Fiocruz. Rio de Janeiro-RJ, Brazil.
[3] Centro Universitário de Valença. Valença-RJ, Brazil.

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An explosion of vulnerabilities

Youth living with HIV/Aids normally confront many challenges in their conviviality with HIV infection. The stigma of the disease, whether it was acquired vertically (from mother to baby) or horizontally, often generates the need to manage a secret in social groups of belonging, added to the difficulties of the antiretroviral therapy, like the collateral effects of the medications, which require adaptations of routines, study and or work, a change in eating and sleeping habits, care for the body and for sexuality, and others. These factors can be aggravated by the synergy of the serological condition with certain social markers of difference, influencing adhesion to treatment and promoting psychic illness (CUNHA, 2011).

In ethnographic studies of youth living with HIV/AIDS, with fieldwork from 2007 to 2016 (CUNHA, 2012, 2014, 2018), reports of abandoning treatment and of anxiety and depression were common and associated to family rejection and or rejection by sexual partners because of serological differences. Combined with the exhaustion of having to deal with a chronic disease without a cure, and the difficulty of managing a social identity and its negative associations while still young. For these reasons, it is common for youth living with AIDS to seek support on social networks, especially virtual networks, and psychological and or psychiatric treatment, and the use of psychotropic drugs associated to antiretroviral therapy is common.

It is observed that youth living with HIV/AIDS currently move between "two worlds of AIDS". One world is technological, and includes virtual groups and support networks, meetings and assistance on social networks, and a broad diffusion of communication, prevention and treatment technologies of a biomedical nature that intermediate healthcare, the exercise of sexuality and reproduction, and forge "bio-socialities" (RABINOW, 1999). The second world, despite the existence of these new technologies, remains plunged into basic issues related to diagnosis, treatment and prevention, resulting from deep social inequalities, with undesirable consequences such as illness and even premature death.

The entrance of Covid-19 into the Brazilian scenario brought fear of infection, illness and death, particularly for people who already have a weakened immunological system (FARO*et al.*, 2020). Considering these issues, from September to November 2020we undertook a qualitative and quantitative study with an activist network of youth living with HIV/AIDs, through its virtual organization, to understand the impact of the new coronavirus on access to care and adhesion to treatment. The study examined the possibility of aggravation of prior emotional difficulties and the emergence of new ones, with consequences for the physical and mental health of this group.

An exploratory moment in the field indicated important aspects for the realization of the study, such as: a) increased crises of anxiety among youth living with HIV/AIDs because of the sense of greater vulnerability to the infection, with increased fear of death because of immunological weakness; b) increased anxiety because of social distancing; c) fear of lack of medication at healthcare services, among those using imported medications; d) fear of lack of supply of antiretroviral

medications that could be used to treatCovid-19; e) increased precariousness of socio-economic conditions, because of unemployment or loss of informal work; f) difficulties with logistics to pick up antiretroviral medication because of lack of circulation of intermunicipal buses, among people who live in one city and receive care in another; and g) development of symptoms of the disease (AIDS) and difficulty in gaining hospital admittance because of the allocation of most hospital beds to patients with Covid-19.

These issues point to vulnerabilities at various levels (AYRES, 2009), and a situationthat tends to become aggravated, given that after 27 months of the Covid-19 pandemic, Brazil officially accumulated 32,358,018 cases and more than 671 thousand deaths through late June 2022.

The notion of vulnerability, which has been emergent in the global public healthcare context, since the experience of the HIV/Aids pandemic (MANN, 1993; AYRES, 2009), refers to different degrees and natures of susceptibility of individuals and collectivities to infection, illness, or death from the disease, considering social, programmatic, and individual aspects that result in the presence or scarcity of resources to deal with the problem and confront it.

These analytical dimensions conform to three levels of vulnerabilities: individual, social, and programmatic. The first concerns individualized aspects (biological, behavioral, emotional) that give rise to exposure and susceptibility to the condition in question. The second is related to the social contexts and to the socially configured relations that influence the individual aspects. Meanwhile, the third refers to the mode and meaning in which the technologies already operating in these contexts (political, programs, services, actions) influence the individual and collective situation (AYRES, 2009). The social, programmatic and individual aspects are inseparable, therefore, networks of social and political support and the economic assistance policies permeate the three levels of vulnerability.

Although AIDS and Covid-19 have different characteristics and aspects, which range from the type of infection to how societies and governments respond to the coronavirus pandemic around the world, the AIDS pandemic has many lessons to offer experiences with Covid-19, as well as points in common when considering the social determinant of health, and the consequent harmful consequences of avoidable illness and death (ABIA, 2021).

In this sense, the notion of social support is considered a central issue. When related to social relations and connections among people and groups, this support involves family, informal groups (self-help) and formal institutionalized groups, such as civil society organizations, which can compose other support networks (CANESQUI; BARSAGLINI, 2012). In social space, these organizations, as the AIDS experience exemplifies, reinforce the political and collective face of certain illnesses, combining demands, social participations, and establishing connections and learning among the participants (ADAM; HERZLICH, 2001).

Thus, our proposal in this study is to conduct an initial discussion based on the preliminary research results, to reflect on the role of social support networks in the experience of youth and adults living with HIV/AIDS, belonging to the Rede Jovem Rio+ [the Rio Network of Positive Youth], and their impacts on mental health in the context of Covid-19.

The research, its subjects, and social markers

The work is supported by a transversal study whose field of investigation was the social and activist network Rede Jovem Rio+[the Rio Network of Positive Youth] which has 300 active youth and adults members who live with HIV/AIDS in the state of Rio de Janeiro, organized in a Facebook group open only to members of the network. The information was collected with an anonymous, online questionnaire, and the data collection took place from September to November 2020, at a time of flexibilization of social distancing. Through objective and open questions, sociodemographic variables were considered as well as those concerning psychological and or psychiatric, social and financial support during the pandemic.

The profile of the sample and other objective issues are presented in Tables 1 and 2, considering absolute and relative frequencies. The *software R* version 4.0.4 was used for these analyses. Portions of the responses were selected to compose the discussion. To protect the anonymity of the research participants, we used the nomenclature P for participant, followed by an ordinal number referring to the order of responses obtained (example P1, P2). After the statements we present a chart of socio-demographic characteristics of the participants related to the declarations.

The qualitative analysis involved responses such as "discursive practices", that is, "ways by which people produce meanings and position themselves in daily social

relations" (SPINK; FEEZZA, 2013). The term *practice* refers to the idea of action. In this sense, the analysis strives to understand how the notions mentalized are constructed and used. This knowledge allows the production of meaning. To relate discursive practices such as production of meanings, is to assume that meanings are not in language in material form, but in the discourse that makes language a tool for the construction of reality (PINHEIRO, 2013).

The process of interpretation was inspired by the work of Spink and Lima (2013). The analysis began with an immersion in the body of information collected, to allow the meanings to emerge without encapsulating the data into categories, classifications and thematizations defined *a priori*. There is a possible confrontation between the meanings constructed in the research process and the interpretation and those stemming from the prior familiarization with our field of study (bibliographic review) and the theories that support our work.

The study was approved by the Research Ethics Committee of the Universidade do Estado do Rio de Janeiro, Brazil, and earned the Certificate of Presentation for Ethical Appreciation [Certificado de Apresentação para Apreciação Ética] nº 32708720.8.0000.5282. The participants indicated their agreement to participate in the research by signing a Free and Informed Consent Agreement.

Results

The number of participants in the study was 108 with an average age of 34.9. The majority declared their race/color to be black (which includes those who self-described as brown or black), followed by white. In terms of the situation of residence, 30.6% live alone, followed by those who live with a parent (20.4%) and with a spouse (15.7%). Nearly 70% said they had some higher-level education or are college graduates, while 10.2% said they only have high school education. Nearly 80% of the participants said they are male, and 18.5% female. In relation to sexual identity, gays represent some 66% of the population of the study, followed by heterosexuals and bisexuals and only one woman said she was a lesbian (Table 1).

Table 1. Profile of the study sample. Youth and adults living with HIV/AIDS duringthe Covid-19 pandemic, Rio de Janeiro, 2020

Characteristics n=108	n	%
Age		
20-30	41	38,3
31-40	41	38,3
41-50	17	15,9
51 +	8	7,5
Color/race		
White	38	35,2
Brown	42	38,9
Black	23	21,3
other (yellow/Oriental/ Indigenous)	2	1,9
do not know/prefer not to respond	3	2,8
Situation of residence		
spouse	17	15,7
children	6	5,6
mother/father	22	20,4
parents	12	11,1
other relatives	9	8,3
alone	33	30,6
non-relatives/friends	9	8,3
Schooling		
elementary	11	10,2
high school graduate	16	14,8
some high school	5	4,6
college graduate	35	32,4
some college	41	38,0

continue...

Characteristics n=108	n	%
Sex		
female	20	18,5
male	86	79,6
others	2	1,9
Sexual identity		
asexual	3	2,8
bisexual	14	13,0
gay	71	65,7
heterosexual	16	14,8
lesbian	1	0,9
pansexual	3	2,8

Source: the authors, 2021.

Table 2 shows the distribution of respondents who maintained contact with friends, family members, Rede Rio+ or other networks, during the quarantine. The contacts were made through at least one means of communication such as *WhatsApp*, *Facebook*, other social networks, other forms of communication or person-to-person contact. With the members of Rede Rio+, we perceived that the contact was realized by nearly 60% of the participants; while the contact with friends and family was lower. Some 82% of the respondents said they participated in other support networks. In relation to psychological and or psychiatric treatment, we saw that 70% of the participants did not have any treatment of this kind before the Covid-19pandemic, when 22.4% turned to some kind of psychological and or psychiatric support. During the pandemic, a bit over half of the participants mentioned they needed some type of social or financial support and some 34% were unemployed.

Table 2. Psychological and or psychiatric, social, and financial support, of youth and adults living with HIV/AIDS during the Covid-19 pandemic. Rio de Janeiro, 2020

Support networks	n	%
Contact[1] with friends		
Yes	34	31,5
No	74	68,5
Contact[1] with family members		
Yes	36	33,3
No	72	66,7
Contact[1] with members of Rede Rio+		
Yes	65	60,2
No	43	39,8
Participation in other support networks		
Yes	88	81,5
No	20	18,5
Had some type of psychological and or psychiatric support before the pandemic		
Yes	23	30,3
No	53	69,7
Sought some type of psychological and or psychiatric support during the pandemic		
Yes	17	22,4
No	58	76,3
Does not apply[2]	1	1,3
Needed some type of social and or financial support		
Yes	39	51,3
No	37	48,7

continue...

Support networks	n	%
Became unemployed during the pandemic		
Yes, myself	26	33,8
Yes, family member	20	26,0
No	31	40,3

[1]Contact: using at least one means of communication from among *WhatsApp*, *Facebook*, other social networks, other forms of communication or in-person contact. [2]Unsuccessfully sought some type of psychological and or psychiatric support.

Source: the authors, 2021.

Support networks and the central place of activism

The characterization of the research participants points to the epidemiological profile that became predominant in relation to AIDS since the decade of 2000 in Brazil, with the infection predominantly affecting more educated, male homosexual, youth (CUNHA, 2018). Some possibilities for the predominance of this profile are the intensification of AIDS in this population, the result of a lack of prevention policies aimed at gays and other men who have sex with men (MSM) (CALAZANS *et al.*, 2008);the impact of government programs that stimulated the entrance of lower income youth to universities; allied to actions of inclusion in higher education through racial quotas. In addition, the participants who access RJR+ through Facebook are those who have the resources needed to access the internet, and therefore, are socially privileged.

RJR+ is composed predominantly of youth and adult homosexual males. Historically, this group occupies spaces of activism and social support in non-governmental AIDS organizations and in the Rede Nacional de Pessoas Vivendo com HIV/AIDS (RNP+) [the National Network of People Living with HIV/AIDS], creating a practice of solidarity, often supported by a language and sociability that is identified with the gay universe and other MSM. The lower participation of female people in the network reflects this profile. Of the few women present in RJR+, most have been infected by vertical transmission (from mother to baby) with an experience with the disease and treatment that is quite different. With adult age, some migrate to the National Movement of Positive Citizens (MNCP), a network aimed exclusively at women, which aims to contemplate the "specificities of females"

living with HIV/AIDS. The absence of older women in general is related to the stigma of the disease and the secrecy associated to the diagnosis, whether because of moral issues, or the fear of violence in cases of sexual-romantic relationships.

It is notable that most of the respondents no longer fit the category of "youth" (which includes people who are up to 29 years old, according to the World Health Organization). This reveals frontiers specific to the RJR+ for the classification of "youth" (CALAIS, 2018) and the Network's potential as a place for longitudinal social support for its participants.

According to Table 2, we can observe that most of the participants maintain contact with members of RJR+, other NGO-AIDS support networks and groups of sociability, reflecting a psychosocial support provided by activism that has been found in the history of AIDS (SILVA, 1998; GALVÃO, 2000; BASTOS, 2002; VALLE, 2002). This data shows the central place of support that the social support networks, particularly RJR+ have for youth and adults living with HIV/AIDS, above all in aggravated situations such as those experienced with Covid-19.

The considerable number of respondents who sought psychological and or psychiatric support demonstrates that, in psychosocial terms, the new coronavirus pandemic created an additional element of stress, aggravating the mental health of the participants of RJR+, as indicated by the statements: "[I feel] more alone, sad and with existential questions more exposed,[which was] latent before the Pandemic" (P78); "[this is all] draining, worrisome, causing deep anxiety" (P90); "[I become] depressed, I have to pick myself up" (P92).

In addition to the impact of the loss of employment of a family member during the pandemic, and of their own possible jobs, the participants recognized an increased cost of living and the need for additional support to maintain ordinary expenses. For those who lost employment in the period, the aggravation of psychic suffering was blatant: "at first it was quite difficult, the company where I worked closed, I was lucky that another called me, but at first I was thinking about what I would do after the insurance ended" (P29); "I've been very depressed, I lost jobs, I hardly go out, I feel tired and discouraged" (P22); "this sense of impotence…as if the unemployment wasn't enough" (P6).

Chart 1. Socio-demographic characteristics of the participants related to the statements

Participants	Characteristics
P78	40, cisgender man, gay, race/color black, lives alone, college graduate, formal employment.
P90	49, cisgender woman, heterosexual, race/color brown, lives with children, high school graduate, unemployed.
P92	34, cisgender man, bisexual, race/color white, lives alone, unfinished college, informal work.
P29	32, cisgender man, gay, race/color black, lives with spouse, college graduate, formal employment.
P22	41, cisgender woman, heterosexual, race/colorwhite, lives with spouse and daughter, did not finish high school, informal work.
P6	30, cisgender man, gay, white, lives with parents, high school graduate, unemployed.

Source: the authors, 2021.

Concerning the need for additional financial support, we see that most of the support comes from emergency assistance of 600 reals a month (approx. US$ 120) paid at that time by the federal government. This type of support demonstrates the importance of public policies that minimize the effects of increased precariousness of living caused by Covid-19, and that directly impact well-being and healthcare. Returning to the concept of vulnerability, these policies directly favor groups or individuals who are legally or politically fragile, by promoting, protecting, or guaranteeing their rights as citizens (AYRES, 2009).

The belonging of youth and adults living with HIV/AIDS to RJR+ and to formal groups (NGOs) and informal ones, whether in-person or virtual, serves as an additional measure of emotional, social and even economic support. This suggests the important role of mutual support and solidarity in responding to pandemics, such as HIV/AIDS and now Covid-19 (ABIA, 2021). However, these networks are not sufficient for certain situations of suffering, which indicates the need for psychological and or psychiatric care and for public policies aimed at reducing social inequalities.[1]

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Note

[1] C. C. da Cunha and A. L. da Silva Junior: conception, planning, analysis, interpretation and writing of the manuscript. L. Stochero: analysis, interpretation and writing of the manuscript. L. A. de Almeida: planning and interpretation of results. W. L. Junger: conception, planning, interpretation and writing of the manuscript.