



# People living with HIV and changes in the daily routine arising from the COVID-19 pandemic

*Pessoas vivendo com HIV e mudanças na rotina diária decorrentes da pandemia da COVID-19*

*Personas que viven con HIV y cambios en la rutina diaria derivados de la pandemia COVID-19*

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## ABSTRACT

**Objective:** to identify the changes in the routine of people living with HIV resulting from the COVID-19 pandemic. **Method:** a qualitative research study, developed through a semi-structured interview, with 46 people living with HIV treated at a service specialized in infectious diseases in the inland of Minas Gerais, Brazil. The data were submitted to lexicographic analysis, with the aid of the IRaMuTeQ software, using the methods of Classical Textual Statistics, Word Cloud and Descending Hierarchical Classification. **Results:** distinct changes were identified in the daily routine of people living with HIV due to the COVID-19 pandemic, including the use of preventive measures, such as wearing a mask and social isolation, in addition to changes in the work and leisure environment, in family life, individual emotional aspects and treatment. **Conclusion and implications for the practice:** many changes, challenges of a physical, biological and psychosocial nature have been shown by the participants in the face of the global pandemic scenario, mainly resulting from social isolation. To this end, coping strategies become essential in the everyday lives of people living with HIV in order to guarantee continuity and uninterrupted treatment, and the prevention of a syndemic, thus mitigating the repercussions of COVID-19 on the health of the individuals who belong to the risk group.

**Keywords:** Coinfection; Coronavirus Infections; HIV Infections; Pandemics; Social Isolation.

## RESUMO

**Objetivo:** identificar as mudanças na rotina das pessoas vivendo com HIV decorrentes da pandemia da COVID-19. **Método:** pesquisa qualitativa, desenvolvida por meio de entrevista semiestruturada, junto a 46 pessoas vivendo com HIV atendidas em um serviço especializado em doenças infectocontagiosas do interior de Minas Gerais, Brasil. Os dados foram submetidos à análise lexicográfica, com auxílio do software IRaMuTeQ, pelos métodos de Estatística Textual Clássica, Nuvem de Palavras e Classificação Hierárquica Descendente. **Resultados:** foram identificadas distintas mudanças na rotina diária de pessoas vivendo com HIV decorrentes da pandemia da COVID-19, dentre elas, o uso de medidas preventivas, como a utilização de máscara e isolamento social, além de mudanças no ambiente de trabalho e de lazer, no convívio familiar, aspectos emocionais individuais e de tratamento. **Conclusão e implicações para a prática:** muitas mudanças e desafios de ordem física, biológica e psicossocial demonstraram serem vivenciados pelos participantes diante do cenário mundial pandêmico, decorrentes, principalmente, do isolamento social. Para tal, estratégias de enfrentamento tornam-se fundamentais no dia-a-dia das pessoas vivendo com HIV visando garantir a continuidade e tratamento ininterrupto, e a prevenção de uma síndrome, mitigando, assim, as repercussões da COVID-19 na saúde destes indivíduos que pertencem ao grupo de risco.

**Palavras-chave:** Coinfecção; Infecções por Coronavirus; Infecções por HIV; Pandemias; Isolamento Social.

## RESUMEN

**Objetivo:** identificar los cambios en la rutina de las personas que viven con VIH como resultado de la pandemia de COVID-19. **Método:** investigación cualitativa, desarrollada a través de una entrevista semiestructurada, con 46 personas que viven con VIH atendidas en un servicio especializado en enfermedades infecciosas en el interior de Minas Gerais, Brasil. Los datos fueron sometidos a análisis lexicográfico, con la ayuda del software IRaMuTeQ, y utilización de los métodos de Estadística Textual Clásica, Nube de Palabras y Clasificación Jerárquica Descendente. **Resultados:** se identificaron distintos cambios en la rutina diaria de las personas que viven con VIH debido a la pandemia de COVID-19, incluido el uso de medidas preventivas, como la utilización de barbijo y aislamiento social, además de cambios en el entorno laboral y de ocio, en la vida familiar, en aspectos emocionales individuales y en el tratamiento. **Conclusión e implicaciones para la práctica:** muchos cambios y desafíos de naturaleza física, biológica y psicossocial han atravesado a los participantes ante el escenario de la pandemia global, principalmente debido al aislamiento social. Para ello, las estrategias de afrontamiento se vuelven imprescindibles en el día a día de las personas que viven con VIH a fin de garantizar la continuidad y el tratamiento ininterrumpido, y la prevención de una síndrome, con el objetivo de mitigar las repercusiones del COVID-19 en la salud de estos sujetos que pertenecen al grupo de riesgo.

**Palabras clave:** Coinfeción; Infecciones por Coronavirus; Infecciones por VIH; Pandemias; Aislamiento Social.

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## INTRODUCTION

The coronavirus disease 2019 (COVID-19) pandemic, until June 2021, caused more than 176 million confirmed cases and 3 million deaths worldwide<sup>1</sup>. The rapid spread of the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) virus and the exponential increase of contagion generated serious health, social, economic and political impacts to the nations<sup>2</sup>, with a consequent change in the routine of the entire population.

Among the most affected by coronavirus infections, individuals who belong to the risk group due to chronic diseases stand out; such as immunocompromised people, like people living with HIV (PLHIV), which present higher risk of exposure and worsening of the disease before coinfection<sup>3</sup>.

The implementation of quarantine, and of social distancing and isolation, as well as other preventive measures, are the main changes in the habits of the population. Social isolation alone, specifically represents a risk factor for health problems in the general population, as it can dramatically increase the feelings of isolation and loneliness in the pandemic period, which can be exacerbated by specific challenges faced by PLHIV who should adopt extra precautions, in addition to maintaining the recommended treatment<sup>3,4</sup>, in order to adapt to the current scenario.

So, numerous were the changes in the routine of the population in view of this pandemic. Thus, this study presents the following questions to be met: Was there a change in the daily routine of people living with HIV after the COVID-19 pandemic? What has changed in the daily routine of these individuals?

Primary studies that point out such changes, particularly among PLHIV were not found in different information resources in the health area, given the world's contemporary situation. Therefore, any initiative that seeks to add new evidence to collaborate in identifying coping with the pandemic by PLHIV is valid, which justifies this study. Thus, the objective of the research was to identify the changes in the routine for PLHIV resulting from the COVID-19 pandemic.

## METHOD

A descriptive research with a qualitative approach, conducted with the PLHIV cared for in a service specialized in infectious diseases in Minas Gerais. The service is the micro-region's headquarters and a reference for 12 adjacent municipalities. The inclusion criteria were as follows: age over 18 years old and knowledge of the confirmed diagnosis of human immunodeficiency virus (HIV) for at least 6 months.

The participants were approached and invited to participate in the study personally by the researcher on the medical appointment, upon delivery of continued-use medications or other demands, respecting their availability and acceptance to participate in the research. It is noteworthy to emphasize that, throughout data collection, there were two refusals to participate after the approach of would-be participants with pain report and scheduled appointment not disposing thus of available time. The number of participants was defined in the course of the field work, due

to theoretical data saturation<sup>5</sup>, aimed at achieving the study objective, respecting the minimum of 20-30 texts recommended by the data processing software<sup>6</sup>. The sample was constituted for convenience.

The data were collected in the period from July to September 2020, through semi-structured interviews conducted in a physician's office of the research unit, a quiet and private environment that was available at the time of collection, respecting the routine and operation of the service. For such end, a semi-structured instrument was used, composed of two parts, elaborated by the research team and qualitatively evaluated by three specialists in the subject matter with respect to face and content validity. The first part had closed questions concerning the characterization of the participants' profile, namely: municipality of residence, age, gender, sexual orientation, marital situation and schooling. The second part included the following guiding question of the interview: Has something changed in your daily routine after the COVID-19 pandemic?

The interviews were recorded on digital media, with a mean duration of 23.54 minutes, and transcribed by the main researcher, being the primary data source that was properly prepared and processed by lexical analysis of the textual corpus, through the *Interface de R pour Analyses Multidimensionalité de Textes Et de Questionnaires* (IRaMuTeQ) software, by the methods of Classic Textual Statistics, Word Cloud and Descending Hierarchical Classification (DHC)<sup>6</sup>.

For this purpose, the active forms of the text segment classes (nouns, adjectives, adverbs, verbs and not recognized forms) were retrieved, which obtained a value  $\geq 3.84$  in the Chi-square test ( $\chi^2$ ); then,  $p < 0.05$ , especially those with  $p < 0.0001$ , as they indicated a strong association between the words in their respective class. From that, data interpretation was based on the assumptions of Thematic Content Analysis<sup>7</sup>.

To analyze the participants' characterization, referring to the closed questions contained in the first part of the instrument, the data were submitted to the IBM® *Statistical Package for Social Sciences trial version 25.0* software, by means of descriptive statistical calculations with absolute and relative frequency and mean.

The study was approved by the Ethics and Research Committee of the Ribeirão Preto School of Nursing, University of São Paulo. All the participants were informed, signed and received a copy of the Free and Informed Consent Form (FICF). For anonymity, an alphanumeric code (participant - P) was used, by order of participation.

## RESULTS

The study included 46 PLHIV, with 31 (67.4%) men and 15 (32.6%) women. The age range of the participants was from 18 to 65 years old, with a mean age of 42.62 years old. As for sexual orientation, 54.3% refer being heterosexuals, 37% homosexuals, 4.3% bisexuals and 4.3% transgenders. In addition, 41.3% of the participants reported being single, 26.1% in stable union, 15.2% married, 10.9% divorced/separated and 6.5% widowed.

Most, 71.7%, of the participants lives in the municipality that is the micro-region's headquarters, while 28.3% live in the surrounding municipalities. As for schooling, 32.6% have complete elementary or secondary education, followed by 10.9% with incomplete elementary education or complete higher education, and 13% with post-graduate studies.

The general text corpus, after processing it in the analysis software by means of basic statistics, was composed of 46 texts divided into 142 text segments (TS) and 4,748 occurrences of words, with 1,081 different words and 626 hapax, with a mean of 103.22 words per text.

By means of the Word Cloud method, the terms of greater recurrence and relevance in the text corpus were identified, based on the frequency, being those that are presented with a larger size and more centrally arranged than the others in Figure 1. In this sense, the ten most frequent active forms in the answers correlated to the changes in the routine research, in ranking ranking, were as follows: no (f=149), be (f=106), people (f=73) why (f=66), more (f=62) stay (f=55) home (f=50), already (f=45), thing (f=44) and very (f=44).

The use of these terms is related to the main changes in the routine of PLHIV, one of them being social isolation, the fact of not being able to go out of the house, being in crowded spaces or performing activities that were previously common in everyday life. In addition, the adverb "no" describes the meaning of the restrictions imposed on people with the pandemic, while the term "why" seeks to explain the reason for certain practices and the word "very" primarily denotes that there were many changes.

Subsequently, through the DHC it was possible to have a deeper understanding of the researched object, which ranked

115 of the text segments retained, therefore obtaining 80.99% leverage, which, by grouping according to the occurrence of words, generated six classes of text segments. Stemming resulted in 774 stems (reduced forms) with 668 active forms. The dendrogram in Figure 2 summarizes the classes, showing the words with associative strength, confirmed through the chi-square test ( $\text{Chi}^2 \geq 3.84$ ), the relationship between the classes, and the percentage in relation to the total of the analyzed corpus.

In the dendrogram, the textual corpus was divided in two independent subcorpora. The first comprises class 1 (17.4%), from which other 4 smaller branches were derived, being the first subdivision, with association of words with each other, classes 2 (17.7%) and 3 (13.9%); and the second, with classes 4 (12.2%) and 5 (26.1%). In addition, the second subcorpus is made up only by class 6 (14.8%), which is opposed to the other classes in lexical terms.

From this, the classes and their respective text segments retrieved were analyzed and interpreted in detail, in order to understand the meaning cores and nominate each one, as described below.

### Class 1 - Knowledge of the exposure to COVID-19 in a systemic context with HIV

Class 1 accounted for 17.4% of the text segments, where the active form which presented an extremely significant association ( $\text{Chi}^2 \geq 3.84$ ;  $p < 0.0001$ ) was: also, still and problem. However, other words also present connectivity among these terms ( $\text{Chi}^2 \geq 3.84$ ), with the following among the main ones, in descending order: place, health and return.

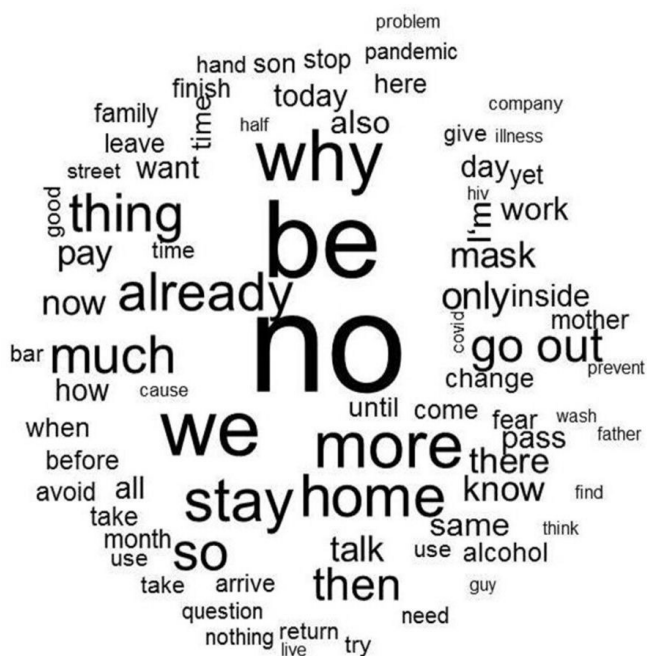


Figure 1. Word Cloud. Minas Gerais, MG, Brazil, 2020. Source: Obtained with the application of the IRaMuTeQ software.

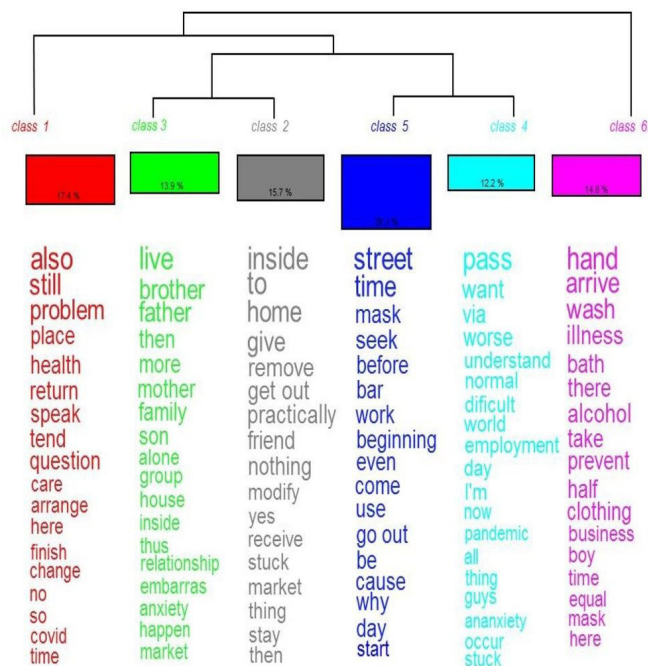


Figure 2. Dendrogram of Descending Hierarchical Classification. Minas Gerais, MG, Brazil, 2020. Source: Resulting from the application the IRaMuTeQ software.

The terms highlighted in this class refer to the changes and understanding of the exposure to COVID in a syndemic context with HIV infections. The highlighted word “also” exposes the understanding of the prevention measures that the participants have used, such as avoiding crowded places, thus recognizing their vulnerabilities.

*I avoid going to very crowded places. The care measures. I also avoid getting close to a lot of people. Because I think like that, I can't take it there because otherwise my house will fall (P34).*

The word “also” reports some difficulties encountered during the pandemic period, mainly related to access to the health services in the treatment of opportunistic diseases, as PLHIV use a public reference system in various specialties. The emergence of such diseases, commonly found with PLHIV, brings a demand for care and assessment of the specialties that are generally not included in the Testing and Counseling Center and the Specialized Assistance Service (*Centro de Testagem e Aconselhamento e ao Serviço de Assistência Especializada, CTA/SAE*), but are part of the Unified Health System (*Sistema Único de Saúde, SUS*). Part of these specialties that work in an outpatient context and are interpreted by the managers as elective suffered restricted care during the pandemic period, as shown in the following statement:

*They have changed also in the question of medical care. [...] Here in the CTA no. But it has already happened that I needed to come here to the CTA and been referred to another hospital and in that such other hospital they told me that they wouldn't do it, because I needed to do a mini surgery, and they said they couldn't do it (P14).*

As an example, the participant reported the delay in the treatment of a diagnosed opportunistic disease, Human Papillomavirus (HPV).

*If I don't treat it, over time, it can evolve and turn into cancer. So I need to do this surgery. Which I haven't done until today and I go there and the doctor said this to me directly: We're not treating people that don't have cancer yet. We're doing surgeries on people who are on the brink of death, understood? In other words, she simply said so, she expects you to have cancer and we'll do your surgery. This was what bothered me the most (P14).*

Such data portrays the changes generated by the pandemic in the indirect treatment of some participants, as they refer to diseases that are secondary to HIV and which, if not treated, impact on the health of these individuals. Such situation occurred when closing the service for other specialties for five months, due to the restriction of the red COVID-19 phase in the city, only treating specific cases referred as urgent.

It is to be emphasized that, in contrast to the previous statements, another report signaled an improvement in the

treatment with the dispensing of ART for a longer period of time, as it avoids running out of the medication before the next visit to the service.

*It has changed that I'm taking medication directly, right. Before, I would spend 2 or 3 days without coming here to get the medication. Not now. I come and get 2 and it will run out tomorrow, I've already got it (P39).*

Another term cited with high frequency in this class refers to the adverb “still”, indicating that the changes have occurred and have persisted for some time. They show that restrictions in people's lives generate insecurity and the desire to return to normal, as described in the textual fragments below.

*It changed a lot. It's starting to reopen, but mass hasn't started yet (P26).*

*It changed. Mass is over. No more seats. No more leisure. It's coming back. But it's still very confused (P44).*

In addition, the word “problem” portrays a context related to work and COVID-19 itself as another threatening health problem experienced by these individuals. This is a condition that emerges exacerbating disorders that were previously present in the lives of PLHIV, as described in the participants' statements.

*In fact, it was a misuse of function, I was punished and they sent me there. That's why I ended up having other problems and I was retired due to problems that originated not only from there, but from other situations as well, you know (P21).*

*Look, I watch TV every day at night and in the morning. I watch it on TV, but I, due to this problem of mine, I don't try to keep putting a lot in my head (P12).*

## **Class 2 - Social Isolation as a change in the daily routine of PLHIV**

Social isolation and/or distancing is represented in class 2, responsible for 17.7% of the text segments, as one of the main changes in the participants' routine. This was revealed in the statements through words like “inside” and “house”, which were strongly significant ( $\text{Chi}^2 \geq 3.84$  and  $p < 0.0001$ ), as well as others such as “remove” and “stuck” ( $\text{Chi}^2 \geq 3.84$ ). These terms point to a context of actions and difficulties found in coping with the COVID-19 pandemic, as evidenced in the following text segments.

*Practically four months inside the house. Apart from going to the market or the pharmacy, doing things for her, things like that (P33).*

*I don't go out anymore. I didn't notice much change, no. This one for me is the biggest. Because we get stuck inside the house. I work inside the house. I'm teaching*

*online, so the business has changed a lot. I had to learn many things (P35).*

In some reports, there are statements suggestive of changes in behavior and emotions in the home environment, triggered by social isolation. The verb “remove” indicates that aspects related to social life were suppressed in view of the new lifestyle imposed by the pandemic.

*Do I need to answer? Jesus Mercy. Guys, I can't stand being inside the house. I can't stand 24 hours with my son on the head. I can't stand. It's tense. It's tense. Changed my mood. The girls say that I'm bipolar (P43).*

*Because we just get stuck. Covered face for no one to see. Can't go out much. It removed my gym, my church, we used to go to the Catholic church, I'm not going anymore because it's closed. It has changed a lot (P26).*

In some reports, the term “go out” refers to the act of going out of the house as a risk of exposure to COVID-19 associated with HIV, denoting doubts about having HIV and sometimes the feeling of fear. In another situation, it is reported as a restriction imposed by the children to exercise an act of care and zeal with parents who are known to be HIV positive.

*It changed. Now I don't go out of the house. I practically go out only for very essential things like that and to work (P02).*

*I'm scared to death. I don't know if, for having HIV, it harms me if I get it. I was really scared. I wasn't going out of the house for anything. Just that, I was distanced from my service (P23).*

*Had to get stuck. Trapped inside the house. My kids don't let me go out. They're scared to death. For me, going to see my mother is a sacrifice (P37).*

### **Class 3 - Family life and its organization in times of COVID-19**

Given social isolation and the consequent restriction on going out of the house, family life was intensified. In this class, comprising 13.9% of the text segments, the verb “to live” ( $\text{Chi}^2 \geq 3.84$  and  $p < 0.0001$ ) and the nouns “brother”, “father”, “mother” and “son” are observed ( $\text{Chi}^2 \geq 3.84$ ), alluding to how families are structured and how restrictive and preventive measures were organized in the family environment.

*Because if someone has it inside the house, the first strategy is who will take care of us. Then, we're going to try not to catch it among ourselves. I, my sister and my brother-in-law are living there, now. But my mother and father live in another house and we're always seeing each other as it is very close. It has totally changed, we don't touch each other anymore, until we're sure that everyone is there (P21).*

*It has changed a lot. Just me and my son live here. It has decreased a lot, we no longer have contact with people as we used to. It has changed because we don't have contact with people anymore. If you go to the market, everything is fast, that fear (P30).*

Inherent to family life, the concern with care so that contamination of family members does not occur stands out. Some conflicts also arise for the children to respect the risky condition of vulnerable parents.

*So everyone stays, for example, me in my room, my father in his, my brother in his, but in communication all the time. Helping ourselves, this has changed in our routine. Now I'm more at home, because my father is in a risk group and I stay more at home (P22).*

*For me it was more this concern of not wanting to take it to my family. Today I live alone, but I have my mother who lives in São João Del Rey, who is an aged lady (P17).*

*Then there comes in the prayer group asking, I ask a prayer for my mother who is intubated, down there you put there who asks is the killer son, okay. I get it heavy, he's not a child not more. They're adults (P45).*

Another aspect signaled by the participants is food. Reports of changes in the eating habits appear as a significant change mentioned by the families.

*It changed. I'm eating a lot. I discovered that I can cook. I can do different things, I discovered this in the pandemic. And always staying home (P22).*

The intense pandemic period experienced in family led to conclusions and allowed reflecting on several family life axes never before realized. The term “then” shows the most relevant conclusions referred to by the participants. The reports describe antagonistic feelings of conflict and approach in family relationships.

*This brought a lot of acceptance in the house, in sense of: Who is with us? Are we alone or are we not alone, so there was a lot of disruption in interpersonal relationships (P21).*

*That changed. My approach is daily, with family and I, it has grown more (P22).*

### **Class 4 -Emotional aspects and coping strategies in times of COVID-19**

Class 4 shows 12.2% of the segments of text, presenting as terms of greater reference ( $\text{Chi}^2 \geq 3.84$ ) verbs such as “be over”, “want” and “understand”, highlighting the sense of the changes that occurred and the desire for the return of the so-called “normal”. The participants reported the emotions they experienced during

the pandemic. Terms such as “worse” and “difficult” were also cited in segments with intensity connotation.

*[...] it can be more of others also wanting to stay more at home, they started to see things that they didn't see when they were not at home. Or that were not talked when we were in that thing from outside (P21).*

*Not only mine, but several people's from Brazil who are going through the worst time today. The worst difficulty, worse than I (P31).*

*[...] I'm very much stressed. It'll be over. But I calm down (P43).*

*It has changed. Because we get more concerned, because we think so, it's already a pandemic, it's catching everywhere, if it catches me, like it or not what I think, we already expect a worse thing to happen (P14).*

### **Class 5 - Changes in the daily routine: working and socializing**

The reports of this class, which retained 26.1% of the text segments, through the terms “street” ( $\text{Chi}^2 \geq 3.84$  and  $p < 0.0001$ ), “mask”, “seek”, “bar” and “work” ( $\text{Chi}^2 \geq 3.84$ ) make a strong reference to the changes in the daily routine, and especially in relation to work. Dissatisfaction resulting from the restriction to go outside only for the essential activities and the desire to go out as an important social aspect to meet friends and talk are observed.

*I go out alone on the street if necessary, like today that I had to go see the doctor (P25).*

*It's still a little difficult because I'm a very, shall we say, very sociable person. I like to go out, like a good party, like to work, at times I like to sit on the street just to chat with my friends (P11).*

PLHIV experience the demand to fetching medications on specific dates, which strengthens adherence to the Antiretroviral Therapy (ART) and this habit has been maintained during the pandemic in this study, despite the fear of going out the house, given the recognition of the importance of treatment.

*Ah, this is already driving me crazy, yes girl. I'm afraid to catch it, Our Lady in Heaven. I avoid going out on the street. I come only to fetch the remedy, only that (P09).*

Regarding work, there is a permeating effect of several changes influenced by the pandemic, such as the home office, which was scarcely known, or the reduction of the workday or distancing, and where contact with several people is described, reasserting the risk for being a PLHIV.

*Totally. It has changed because mainly because I was working, I had a workload. I had a bar, had a restaurant*

*that turned into a bar later, and when I started to move it, when the customers were coming, had to close because of the pandemic (P33).*

*This has changed because I'm working from home office. Since March 17<sup>th</sup>. I had a few times. 15 in 15 days I will take the test in the company because it is needed to be able to be going, but even more to monitor the diagnosis. Company guidelines that kept me distanced (P28).*

Using the mask emerges in this class as a reference to the protection required to leave the home environment. Some participants state that they adapted to the daily routine and recognize the importance of its use, but also verbalize difficulties and even the manifestation of symptoms arising with constant mask use.

*But at first I was too scared to pick it up and go out and be contaminated. With my luck I will catch it and die. I will die on the same day. I'm wearing a mask when I go out (P03).*

*We get more afraid to go out sometimes, right? You have to use such a mask that is horrible. We get more tired than normal... Because people's breath is compromised (P38).*

### **Class 6 - Preventive measures as a way to reduce the impacts of COVID-19**

Finally, class 6, accounting for 14.8% of the text segments, presented a high significant association ( $\text{Chi}^2 \geq 3.84$ ;  $p < 0.0001$ ) with the following active forms, in descending order: hand, reach, wash, disease, bath, alcohol, take, prevent and clothes. Therefore, they indicate preventive measures for COVID-19 as a change in the routine. Among them are the care measures mainly focused on external environments such as hand hygiene and mask use, as per the participants' statements.

*Mask use, hand hygiene whenever possible, using alcohol or washing hands (P18).*

*I'm just so like this, like rule-made type: avoid overcrowding, avoid going out and avoid going out without the mask. I wash my hands a lot, asepsis? As there is general consensus that it's the same general rule for us to do (P41).*

In addition, the care measures when entering the home environment in order to safeguard, in particular, the health of family members, were revealed as major concerns impacting on the behavioral changes.

*All the same, I get home now, take off everything, wash everything, I shower, my wife... we leave it to do everything together (P44).*

*So well, I get to my mother's house, the first thing I do is take a shower, take my clothes off and then I'll compliment her as she knows. Because I'm afraid to take disease to her (P17).*

## DISCUSSION

COVID-19 significantly changed the routine of the entire population. However, for PLHIV, such effects can be significant not only in the psychological and social aspects of their lives, but also as regards the biological aspects given the weakness of their immune system from the diagnosis established, recognized by the participants in this research. Thus representing an increased risk for infection and complications related to COVID-19, in addition to the progression of the HIV disease, particularly in patients whose illness is not adequately treated<sup>8</sup>.

Proposals are discussed given the need to act in the face of the challenges that emerge when observing a possible syndemic, or two or more epidemics, in the case of COVID-19 and HIV. Actions that go beyond structural factors and surveillance of these diseases and include biological, behavioral and psychosocial aspects<sup>9</sup>, as clearly described in the statements.

Social isolation and/or distancing is the main preventive measure adopted by all countries in the world during the pandemic. However, PLHIV need regular health monitoring, for example, performing semi-annual monitoring of CD4 and Viral Load or fetching medications intended for the treatment, in addition to treating opportunistic infections commonly found in PLHIV. Therefore, correct treatment of HIV and even of other diseases linked to it, as evidenced in this study, can sometimes be interrupted or impaired in view of such a preventive measure<sup>8</sup>.

Thus, enormous challenges permeate the maintenance of care and general assistance to PLHIV. These range from access to tests and delay to start ART to city blockages that slow down resource continuation and allocation for people. Therefore, the WHO, UNAIDS and the Global Network of PLHIV proposed strategies and, among them, the dispensation of ART in doses of 3 to 6 months in order to reduce the number of visits to the treatment centers, as seen in one of the participants' statements. Thus, they guarantee the supply of medications and also of inputs such as condoms, thus facilitating non-interruption of treatment and potentially favoring harm reduction. Various study strands suggest that ART interruption can cause changes not only in physical health, but also issues related to mental health<sup>10</sup>.

It should be noted that, in this study, impairment in direct HIV treatment was not identified, as most people emphasized going out of the houses only to fetch the medications. However, the treatment of opportunistic infections, such as HPV in one of the participants' reports, was impaired, which could negatively impact on the health of this user.

The pandemic has marked a context that brings out the diversity and complexity of family life. The coexistence imposed by social distancing and the "Stay home" slogan contributed to the approximation of people and caused conflicts, ruptures and reflections on death and finitude at the same time<sup>11</sup>. Such findings were also found in the reports by the participants of this research that signal the concern of adopting the recommended care measures seeking to prevent contagion and transmission of COVID-19 to the family members, which is also one of the sources for conflicts in the isolation period.

Another change that appears in the family context arising from social isolation is eating habits. In general, PLHIV are advised to improve their eating habits in order to strengthen their immune system. With more time at their homes, people began to spend their time in preparing their own food and, thus, had the opportunity to follow a healthy diet<sup>12</sup>.

Although social isolation and/or distancing is intended to benefit the physical health of the population, this guideline can be harmful to social and emotional health. Consequently, it is noted that increased anxiety has been prevalent worldwide<sup>8</sup>. The CDC observed that individuals with chronic diseases, such as HIV, can develop a stronger stress response than the rest of the population, resulting from the increased risk of contracting COVID-19 due to having the immune system impaired<sup>13</sup>, which converges with the findings of this study.

It is known that PLHIV are more likely to develop depression than those living without the virus<sup>14</sup>. Therefore, the social distancing necessary to fight against COVID-19 can increase loneliness, given the lack of social interaction, which may come to exacerbate depressive symptoms in the general population, but especially in PVHIV, especially newly diagnosed individuals<sup>8</sup>, not included in this study. Thus, it is worth highlighting the need for actions aimed at the stress related to COVID-19, because they have repercussions on the mental distress of the population through disorders like depression and anxiety, previously mentioned.

A research study points out that the Telehealth method, employed as data collection, has provided an option to help people in difficult isolation times. The findings describe that feelings such as loneliness and stress were obtained in reports by telephone contact. Also reporting the possibility of helping PLHIV by offering support and guidance, keeping them connected to a health system<sup>15</sup>.

It is known that work has a strong relationship in people's lives. It is present in the routine changes and has enormous importance in the personal, social and economic relationships. The exercise of the so-called "home office" already exists in the working world; however, its practice was an exception that ended up becoming the rule for several branches of activities during the pandemic, even for some participants of this research. The home environment began to share space with work, school, and domestic and leisure activities. Then come a number of challenges: people staying "online" and responsive, developing rapid learning of new technologies and communication, improving time management and meeting the business-related work demands. All this respecting family life, leisure moments and physical and mental rehabilitation in the home environment<sup>16</sup>.

With regard to the preventive measures performed by the interviewees, the following stand out: social isolation, already discussed, mask use and hand hygiene with soap or 70% alcohol, as well as clothes and body hygiene when coming into contact with potentially contaminated sites. Certain amplification of such practices by these individuals given the chronic condition related to their immunological fragility is noticed. Such practices, as well as increased care with their health condition, converge with the fundamental recommendations to contain the rapid transmission of COVID-19<sup>17,18</sup>.

## CONCLUSIONS AND IMPLICATIONS FOR THE PRACTICE

In view of the findings, it is noted that the COVID-19 pandemic impacted several changes on the daily routine of PLHIV, as reported by the participants, from the work and leisure environment to family life, individual emotional aspects and related to treatment. It is worth mentioning that social isolation, one of the main recommended preventive measures, was responsible for triggering most of the reported changes, mainly those related to the emotional and psychological aspects experienced during this period.

Therefore, many challenges were shown to be experienced by the participants in this world scenario. For this, coping strategies were pointed out as a way to minimize such impacts. Among these, access and maintenance of correct and uninterrupted treatment with ART, through availability for a longer period of time, aiming to ensure good quality of life. In addition to that, complying with preventive measures, such as mask use and social isolation, became part of the everyday life of the population as a whole, but especially of PVHIV, in order to mitigate the repercussions of COVID-19 on the health of these individuals belonging to the risk group.

The study presents limitations regarding the data, given the single geographical context that was defined. Thus, it becomes necessary to conduct more studies on the researched phenomenon that present various social realities and that add more knowledge, in addition to the new findings presented.

The research offers contributions to the advancement of scientific knowledge in the health area, also including Nursing, by identifying changes in the daily routine of PLHIV given the COVID-19 pandemic in the Brazilian scenario, a context still little explored, evidencing important issues related to the real adversities and coping strategies experienced by this population. Thus, it will become possible to develop guidance plans, public policies and managerial and care strategies that promote the reorganization of health care processes to cope with this problem.

## AUTHOR'S CONTRIBUTIONS

Study design. Tassiana Maria Vieira Pereira. Elucir Gir.

Data collection or production. Tassiana Maria Vieira Pereira.

Data analysis. Tassiana Maria Vieira Pereira. Andressa Silva Torres dos Santos.

Interpretation of the results. Tassiana Maria Vieira Pereira. Elucir Gir. Andressa Silva Torres dos Santos.

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