

Social representations of antiretroviral therapy for people living with HIV*

Representações sociais da terapia antirretroviral para pessoas vivendo com HIV

Las representaciones sociales de la terapia antirretroviral para las personas que viven con el VIH

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Abstract: Objective: analyzing the social representation of antiretroviral therapy for people living with HIV. **Method:** a qualitative study using the Theory of Social Representations. Data collection included 50 participants, being performed from February to September 2020 using a sociodemographic characterization questionnaire and a form for free evocations. The study scenario was an HIV treatment unit in the metropolitan region of Rio de Janeiro. Data analysis was performed by the EVOC software. **Results:** the central nucleus of the representation of antiretroviral therapy reinforces HIV control and the image of the drug as something good. **Conclusion:** the representational structure suggests that the group tends to normalize antiretroviral therapy, referring to a drug that controls HIV. The study made it possible to recognize the different representational contents of antiretroviral therapy for the studied group, in addition to the varied complexity among the images identified.

Descriptors: Anti-retroviral agents; Antiretroviral therapy, Highly active; HIV; Nursing; Treatment follow-up and compliance

Resumo: Objetivo: analisar a representação social da terapia antirretroviral para pessoas vivendo com HIV. **Método:** estudo qualitativo com a utilização da Teoria das Representações Sociais. A coleta de dados incluiu 50 participantes, sendo realizada de fevereiro a setembro de 2020 utilizando um questionário de caracterização sociodemográfica e um formulário para evocações livres. O cenário do estudo foi uma unidade de tratamento de HIV na região metropolitana do Rio de Janeiro. A análise dos dados foi realizada pelo *software* EVOC. **Resultados:** o núcleo central da representação da terapia antirretroviral reforça o controle do HIV e a imagem do medicamento como algo bom. **Conclusão:** a estrutura representacional sugere que o grupo tende à normalização da terapia antirretroviral, fazendo referência a um medicamento que controla o HIV. O estudo possibilitou reconhecer os diferentes conteúdos representacionais da terapia antirretroviral para o grupo estudado, além da variada complexidade entre as imagens identificadas.

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Descritores: Antirretrovirais; Terapia antirretroviral de alta atividade; HIV; Enfermagem; Cooperação e adesão ao tratamento

Resumen: Objetivo: analizar la representación social de la terapia antirretroviral para las personas que viven con el VIH. **Método:** un estudio cualitativo utilizando la Teoría de las Representaciones Sociales. La recolección de datos incluyó a 50 participantes, realizándolos de febrero a septiembre de 2020 utilizando un cuestionario de caracterización sociodemográfica y un formulario para evocaciones libres. El escenario del estudio fue una unidad de tratamiento del VIH en la región metropolitana de Río de Janeiro. El análisis de los datos fue realizado por el *software* EVOC. **Resultados:** el núcleo central de la representación de la terapia antirretroviral refuerza el control del VIH y la imagen del fármaco como algo bueno. **Conclusión:** la estructura representacional sugiere que el grupo tiende a normalizar la terapia antirretroviral, refiriéndose a un fármaco que controla el VIH. El estudio ha permitido reconocer los diferentes contenidos representacionales de la terapia antirretroviral para el grupo estudiado, además de la variada complejidad entre las imágenes identificadas.

Descritores: Antirretrovirales; Terapia antirretroviral altamente activa; VIH; Enfermería; Cumplimiento y adherencia al tratamiento

Introduction

The epidemic of human immunodeficiency virus (HIV) infection is still today a matter of prominence and relevance to public health, as it is estimated that more than 37 million people worldwide live in this condition. It is estimated that 1.7 million new infections were identified in 2019.¹ Ten years after the emergence of the first cases of HIV in 1987, the drug zidovudine (AZT), which was previously used for cancer patients, was indicated as the first capable of reducing the multiplication of HIV. Then, with the creation of the Unified Health System (SUS) and with pressure from activists, in 1991, the supply of AZT becomes free for people living with HIV.²

In 1992, the combination of AZT and Videx inaugurated what became known as a "cocktail". Double therapy was then the only treatment option, based on a high cost and a degree of efficacy below the desired. However, in this circumstance, this reduced mortality due to Acquired Immunodeficiency Syndrome (AIDS) by 50% in Brazil, increasing by 80% the efficacy of the treatment of opportunistic HIV infections.³

After the XI International AIDS Conference, held in 1996 in Vancouver, Canada, the results obtained with three associated drugs: triple therapy, formed by zidovudine, lamivudine and efavirenz, served as a boost for further lawsuits. In 1996, these new drugs became available in Brazil, through Law 9.313/96, which regulates free access to antiretroviral drugs in the SUS.^{4,5}

After more than three decades and several advances, the current antiretroviral therapy (ART) aims to considerably reduce the viral load in the individual's body, reducing mortality and the incidence of opportunistic infections, ultimately generating improvement in quality of life. For this reason, ART has a great impact on the lives of people living with HIV, when used correctly and according to the proposed therapy.⁶

The correct use of ART is related to several important factors for treatment follow-up, since some authors treat this use as the form prescribed by the health professional, respecting its guidelines. Thus, for a satisfactory support, it is necessary to involve the users of this therapy in the choice of their therapeutic regimen and their dosage, since the support is understood as a collaborative process between the professional and the individual, facilitating the maintenance and success of the treatment. In addition, for follow-up to ART to be adequate, 80% of the prescribed doses must be taken, at the risk of consequent therapeutic failure.⁷⁻⁸

Although there are relevant advances in the quality of life of people living with HIV, there are still challenges, especially about adequate treatment follow-up, as adequate follow-up of ART continues to be difficult due to the continuous use of medications.⁴ In addition, after the diagnosis of HIV infection, the individual faces issues related to the difficulties of coexistence and acceptance of the disease, which can cause emotional conflicts that hinder the continuity of ART. This coping process experienced by the individual is important for him to feel confident in the changes necessary for his/her lifestyle in the face of HIV infection, and it is necessary that the professional team develop strategies to help him/her.⁹

In this sense, it is worth reinforcing that the reception by the health team and the provision of health services are factors that impact treatment adherence, so that they become fundamental for the follow-up of ART. Some subjects feel comfortable sharing their doubts and insecurity, a strategy to overcome any obstacles to a satisfactory follow-up. In addition, professional support can contribute to the return of the patient to the service since the individual feels supported when he is well received. This attitude is important, especially at the beginning of treatment in which

emotional overload is greater.¹⁰

The nursing professional should be able to provide humanized care aimed at the individual who has the diagnosis of HIV positive, in addition to the physiological issues involved, valuing other dimensions of human existence. Through nursing consultations, it is possible to construct knowledge in a shared way, to promote the stimulation of therapy follow-up, knowledge about antiretroviral therapy and changes in lifestyle.¹⁰⁻¹¹

Social representations about HIV involve the weaknesses faced, besides producing negative images, even with the advancement of treatment. However, they report the positive perception about antiretroviral therapy related to the chronicity of the disease.¹²

The theory of social representations is adapted to this discussion by providing the elaboration of social knowledge through shared human interactions about the object of this study, allowing the construction of a given reality.¹³ This reference allows, therefore, to know the reality of the studied group, with consequent definition of specific care actions. Thus, from the knowledge common to a given social group, also designated as common sense, this theory provides the construction of a given reality,¹⁴ making it appropriate to use this reference.

Therefore, using the Theory of Social Representations, we intend to identify, analyze and discuss these representations as a mediating element of the relationship between people living with HIV and ART. Having observed the importance of antiretroviral therapy, the objective was: to analyze the social representation of antiretroviral therapy for people living with HIV.

Method

This is a qualitative research, with the Theory of Social Representations in its structural approach. This reference is considered as a way of understanding the impressions of groups about defined social objects, since it allows immersion in the daily lives of the subjects. This theory allows the understanding of the knowledge constituted by a social group, because it recognizes that there are different ways of knowing and communicating, regulated by different objectives.¹⁵

The structural approach places special emphasis on the structuring of cognitive contents, also taking care of their transformation from social practices. It is more focused, therefore, on the constituted aspect than on the constituent aspect of representations and values an experimental methodological orientation. In addition to allowing the study of representational content from the connections of the elements.¹⁶

The study scenario was the Specialized Care Service (SCS) of a municipal health center located in Baixada Fluminense, Rio de Janeiro. It is a reference for the care of people living with HIV in the municipality of Duque de Caxias and surrounding cities. Being an outpatient service, it is composed of offices for individual and confidential care, where the multidisciplinary team works, including doctors, nurses, psychologists and social workers. The study participants were 50 individuals of both sexes, using ART and regularly monitored in this unit, who, invited, agreed to contribute to the study. The inclusion criteria were people with HIV serology undergoing treatment with antiretroviral therapy in this unit; 18 years of age or older. Individuals who were unable to respond to requests independently were excluded from the study.

The invitation to the research occurred at the end of nursing care, and its objectives were explained. In common, members of the studied group have the fact that they live with HIV and maintain follow-up by the health team in the same unit. In total, 14 individuals were not included, due to the inability to produce the requested information. As a result, they did not integrate the group that understood the corpus of analysis, and their participation ended at the end of the collection. None of the users of the service refused to participate or gave up doing so during data collection.

Data collection was performed from February to September 2020, using a questionnaire for the sociodemographic characterization of the group and a form for the registration of free evocations, obtained using the inducing term "anti-retroviral".

Data were collected by the authors of the study, who work at the research site through a university extension project. Thus, they are close to the participants. Prior to the data collection phase, the researchers met for training on the care to be observed for this.

The subjects were asked to utter five words after verbalization of the inducing term by the researchers, recording the terms evoked in a form, observing the sequence in which they were enunciated. The collection was performed individually in a private room.

For data analysis, the collected terms were organized in a spreadsheet and standardized in an evocation dictionary. Next, the corpus was submitted to analysis by the EVOC software, version 2015, which allows organizing the words according to the frequency and order of evocation. From the EVOC use, a table of four houses was obtained, with the terms enunciated by the subjects distributed throughout the four quadrants.

In view of the terms that integrate the table of four houses, the analysis of similarity was performed, which consists of the creation of a graphic structure for cognitive mapping. Thus, it was possible to identify the connection between the words evoked, and to construct the structure of the representation, which also contains the forces of connection between them, expanding the understanding about the object of the study.¹⁷

All recommendations and ethical conduct were followed, in attention to Resolution 466 of December 12, 2012, as well as the ethical specificities of resolution 580 of March 22, 2018. Participation in the study took place voluntarily and with the signing of the free and informed consent form. After consideration by COEP/UERJ, the project of this research was approved through Opinion N° 3,807,397 of January 23, 2020.

Results

In total, 50 people living with HIV were included, 30% aged between 31 and 40 years; regarding gender, 52% were male and 48% female; as for religion, 48% declared themselves evangelical. Regarding sexual orientation, 64% declared themselves heterosexual; there was a predominance of people living alone (64%) and working individuals (64%). Regarding the time of treatment, 48% patients indicated a period of more than 5 years. Regarding antiretroviral therapy in use at the time of data collection, the combination of tenofovir, lamivudine and efavirenz stood out

for 36% of the participants.

During the process of recording and organizing the evocations, there was saturation of the data, as can be observed, as can be seen, as can be observed, by reducing the terms evoked after standardization: from the use of the inducing term "antiretroviral", 222 evocations were obtained, which after standardization resulted in 38 words or expressions, constituting the corpus of analysis.

For the prototypical analysis and, therefore, the four-house chart was obtained, the software Evoc[®], with definition of the minimum, average, evocation order and average evocation rang was used. The minimum frequency corresponding to the number of times a term was evoked was 9; The minimum frequency corresponding to the number of times a term was evoked was 9; the mean frequency was calculated in 12 and the mean order of recall (AOE) indicating the sequential order with which the terms were evoked by the participants of the studied group was calculated by the software at 3.0. Based on these parameters, the software indicated the distribution of the 11 words or expressions obtained in the four quadrants. Table 1 presents the representational contents ordered according to the frequency and AOE criteria.

Board 1 - Table of four houses referring to evocations of the term antiretroviral inducer for people living with HIV. Rio de Janeiro, 2020 (n = 50 subjects, Minf= 9; Averf= 12; Average Rang = 3.0)

AOE**	Rang*** <3,00			Rang ≥ 3,00		
Averf*	Evocations	Freq	AOE**	Evocations	Freq	AOE
≥ 12	CENTRAL NUCLEOUS	26	2.538	FIRST PERIPHERY	21	3.952
		14	3.000			
		12	1.417	Life		
< 11	CONTRAST ZONE	11	2.636	SECOND PERIPHERY	11	3.273
		9	2.556		10	3.800
		9	2.667		10	3.200
		9	2.778			
	Daily Protection Poor Salvation			Normal Dependence Tranquility		

*Averf - Average Frequency; **AOE - Average order of evocation; ***Rang - general average of evocation orders.

The upper left quadrant concentrates terms associated with the central nucleus of the representation, which are evoked in greater quantity and in the first positions. This quadrant indicates the possible central contents of the representation of antiretroviral therapy for the studied group. In it are the terms control-HIV, good and medicine. The term "control-HIV" is related to the group's knowledge about the purpose of ART and presents the highest frequency of analysis (26). In addition, an evaluative element is identified that qualifies art expressed by the term "good" (14), and finalizing, an imagery element of ART in "medicine" (12) is observed and that was the most readily evoked term.

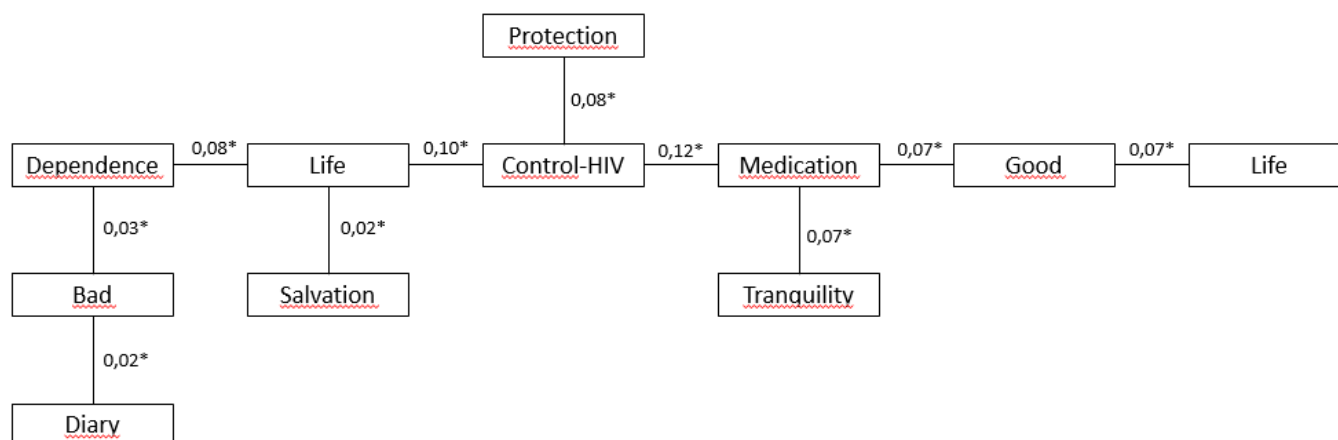
The upper right quadrant (first periphery) presents the word that was also evoked more frequently, but later. It is composed of the term "life" (21), understood as a positive evocation that praises survival as opposed to death associated with the disease in the early periods of the epidemic.

The lower right quadrant (second periphery) consists of the terms that were evoked less frequently and late. In this quadrant, the terms "dependence" (10), "normal" (11) and "tranquility" (10) are included. In these three evocations, a negative element is observed, respectively, referring to the relationship of dependence established between the subject and the medication, an element that refers to the attempt to naturalize ART and a positive element that refers to coping with the disease through medication resulting in tranquility.

The lower left quadrant (contrast zone) is formed by the words that were evoked in a smaller amount, however, more readily remembered by the study participants. In this quadrant are the terms "protection" (11), "daily" (9), "bad" (9) and "salvation" (9). The images of protection and salvation represent a positive attitude towards ART, while the terms "daily" and "bad", negative attitudes associated with the dependence established between the subject and the medication. The negative connotation observed in this quadrant points to a possible variation of the central nucleus, which may indicate a subgroup that assumes less positive positioning in the face of ART.

From the elaboration of the table of four houses, the analysis of similitude was performed,

based on the strength of connection between the terms evoked by the study participants for the term antiretroviral. This analysis is presented in Figure 1, which follows:



*Each value represents the binding force between the terms evoked.

Figure 1 – Maximum tree referring to evocations of the term antiretroviral inducer, Rio de Janeiro, 2020

Figure 1 shows that the words that established the greatest number of connections were "life", with five connections, "control-HIV", with four connections and "medicine" also with 4 connections. The link with the highest index present in the similarity tree is the connection between the words "control-HIV" and "medicine" (0.12); "control-HIV" and "life" (0.10). These two axes follow the other connections between the elements that give meaning to the representations obtained in the study.

The term that presents the strongest links of the analysis is "control-HIV", which binds to "medicine" (0.12), "life" (0.10) and "protection" (0.08). These elements explain the fundamental meaning of ART, conceived as a medicine that provides protection and life to people with HIV.

It is worth mentioning the connections of the elements "dependence" and "life" (0.08), which suggests the conception of this group of the need for ART to continue living, that is, the dependence of ART for life maintenance.

It is also noteworthy the possibility of centrality of the term "control-HIV", which performs different links with relevant liaison forces. The links of "control-HIV" and "protection" (0.08) are highlighted; "life" and dependence (0.08); "medicine" and "good" (0.07); "medicine" and "tranquility" (0.07); "dependence" and "bad" (0.03); "life" and "salvation" (0.02); "bad" and "daily"

(0.02). These connections, as well as the other ART connections for the studied group will be deepened in the discussion.

Discussion

The representations of antiretroviral presented reveal the cognitions of the participants of this study, resulting from the experience of using a continuous therapy for the treatment of a chronic, incurable and highly burdened pathology of stigma.¹⁸ According to the data presented, a set of representational contents was observed that stood out for the studied group.

The probable central nucleus contains terms that structure the group's representation, consisting of "control-HIV", "good" and "medicine". The first element refers to what the group understands as the purpose of the use of ART, and according to some authors, it may portray the familiarity of these subjects by more technical-scientific terms and notions.¹⁹⁻²⁰ In this sense, the term "good" may have the role of reinforcing the favorable action of ART in containing infection.²⁰ The term "medicine" refers to the objectification of ART in an image made to something physical that has an action of treatment and cure/control of a pathology.

The evocation "control-HIV", expressed with the highest absolute frequency, presented a strong connection with the terms "medicine" and "life", showing itself as the organizing term of social representation. These links seem to indicate the main purpose of ART, that is, that of virus control, which, in turn, is not only associated with the use of medication, but also with the idea of being essential for the maintenance of life. Therefore, it is observed that, for the studied group, the protection of life depends on the use of the drug.

In this sense, the connection between "good" and "medicine" reinforces the perception mentioned above, besides suggesting that for this group the use of the drug is important and necessary so that they can obtain quality and life expectancy as good as the population that does not live with HIV.¹⁸

The association between the use of ART and the protection of life is a condition of treatment

achieved more recent, due to the many advances in drug therapy. With the advent and evolution of high-efficacy ART, terms such as self-acceptance and life expectants became part of the daily lives of people living with HIV. Thus, over time there was a remodeling of life with HIV, previously more strongly associated with death, and currently closer to the chronicity of the disease. In this sense, treatment has been recognized as the means to stay alive.²¹

This perception is reinforced by the presence of the evocation of "life", the only component of the first periphery, with a connotation favorable to ART. The importance of the representation of life for ART is relevant, considering that the desire to continue living is fundamental for strong treatment to therapy.²¹

It is important to highlight the need for treatment to strengthen the feeling of valuing life, self-love and the feeling of hope, factors capable of interfering in treatment follow-up.²²⁻²³ For the studied group, the connection of the term "life" with "salvation" tends to strengthen the positive character of the image of "life", seeming to indicate that ART is recognized to ensure survival.

The second periphery seems to indicate an ambivalence of feelings of the studied group: despite the positive character contained in the image represented by tranquility, the indication of dependence seems to contain an unwanted aspect of the use of medication. In addition to these two aspects, it is worth mentioning the apparent tendency of the group to refer to ART as an element of normality. This is evident with the representational contents present in this quadrant, as well as from the connections between "good" and "normal" and tranquility" and "medicine". Thus, an association is perceived between the positive attitude and an element that seeks to point to the normality of life.

These findings reinforce a trend already identified by another author of "positive illusion", in which the subjects could consciously deny themselves, as well as to any situation that may negatively influence the desire for good treatment agreement and resistance to related difficulties.²⁰ It is worth mentioning that treatment is characterized as a great challenge, given the complexity of the therapeutic regimen, changes in routine and adverse reactions.⁷ Therefore, the expression of a

current normality can be configured as a movement of the studied group in order to minimize the possible wear and tear with personal costs, including a medication in the routine and reorganizing customs for the use of antiretroviral therapy.

However, the connection between the terms "dependence" and "bad", observed in the analysis of similarity, reinforce the negative meaning of ART, probably associated with the fact that medication is indispensable for living and the need for daily use, impacting daily life, besides being a reaffirmation of the existence of a disease that needs to be faced. Some individuals who use ART feel that medications constitute a kind of prison to which they are subjected, and that their lives are linked to the schedules, schemes and dosages required by the medications.²²

The contrast zone contains elements with a more negative character, especially when related to other terms in the analysis of similarity that reinforce this idea, such as dependence and daily, and this fact may indicate the possibility of the existence of a subgroup that represents ART in a different way. These negative concepts suggest different experiences and types of individual coping.²⁰

In addition to these terms, in the second periphery, there is also the evocation "dependence", which is content that carries a negative attitude, since it suggests the subordination of these people to ART. Thus, the connection of the words "life" and "dependence" indicates the mandatory use of treatment for the maintenance of life.^{20,22}

Still in the contrast zone, the term "daily" indicates the sense of routine in the use of ART, and the link of "diary" and "bad" in the tree of similitude, tends to point it as something negative. This understanding is reinforced, by studies that point out, the therapeutic schemes, as an aspect that generates difficulty in the performance of ART, a negative aspect related to the adaptation to the daily routine change, there is a relationship between the simplification of the schemes with a satisfactory adement.^{22,24}

The representation of the quadrants of the central nucleus, first periphery and second periphery tend to have a positive position on ART for this group. However, the contrast zone points out negative attitudes. Regarding the social representations of antiretroviral therapy, from the study

data, one can think of two versions, the first related to a normal life with regular use of medications. The second refers to antiretroviral drugs as something that generates dependence and suffering, more characteristic of subjects with irregular/inadequate treatment and low support.²⁵

Among the elements presented by the group, the evocations "bad" and "good" emerged, and these are terms that make an opposite evaluation of ART. This divergence may occur due to the complexity of the relationship with HIV, because it is the cause of an incurable and stigmatized infection with the existence of drugs that can control it.²⁰

It is noticed that the representational contents obtained in the four-house table express a more positive trend on ART, and this result may be part of a process of evolution of social representations of HIV.^{20,26} This evolution can occur when elements related to spirituality are involved in coping with ART and HIV diagnosis.²⁰

In this sense, knowing that social representations allow characterizing the processes and relationships in which social groups establish their impressions about a given object, the identification of these images can help the understanding of the process of medication therapy, as well as the actions of health team professionals.^{16,25} Among the aspects that impact on the therapeutic resource, it is important to highlight that the health team plays a fundamental role in follow-up to treatment.²⁷

It is noteworthy that professionals need to be aware that the support comprises more than the pharmacological issues and involves some subjective and psychosocial aspects of the group, such as: the individual variables; the characteristics of the treatment; the characteristics of HIV/AIDS infection; the relationship with the health service and social support.²⁸

Therefore, it is desirable that health professionals be trained in a technical and scientific way about the medication, besides being prepared for interventions in individual patient issues, aiming at comprehensive care, promoting support and self-care.^{11,29} Therefore, the professional should have knowledge about the pathology and antiretroviral therapy to establish targeted care for people living with HIV, aiming to improve their life expectancy.²³

The study identified the term "daily" and "dependence", and both evocations are connected in the analysis of the term "bad", reinforcing negative aspects of ART. Thinking about it, it is worth mentioning that the beginning of treatment is a critical moment and that it should be built in partnership with the individual, giving subsidies so that the individual can take the attitude of accepting the treatment, actively and positively. Once again, professional health actions are necessary and important to encourage the acceptance of therapy and knowing that this can directly impact medication follow-up.^{22,25}

In this context, the nursing consultation is an important tool for the creation of professional-patient interaction and for a space to encourage the support. Since, during the consultation, in addition to sharing the most subjective questions to treatment and diagnosis, it is also a favorable environment for orientation. The nursing consultation is also a space to identify possible difficulties associated with the onset and regular use of ART, as well as to jointly outline an action plan that makes it possible to minimize the impact of this event.¹²

It is worth mentioning that, as the contact between nursing and the patient advances and becomes more consistent, the difficulties with medication and doubts are minimized and clarified and may promote greater treatment follow-up. People living with HIV tend to have a moment of therapeutic support in the nursing consultation.³⁰

Among the limitations of the study, it was observed difficulties to perform data collection in the period initially planned, in view of the suspension of outpatient services for an important period, due to the COVID-19 pandemic.

Conclusion

This study made it possible to perceive the different representational contents that antiretroviral therapy brings to the studied group, and to identify the relationships of varied complexity between the identified images. The representation of a medication that controls HIV, as a good element for the consolidation of a normal life, found the unwanted aspects that portray ART

as a bad element due to the fact of generating dependence and by daily use.

It was possible to recognize, through the data, the representational structure of ART for the studied group and, from it, some positive and negative aspects to be observed were highlighted to direct the performance of the nursing team, which allows a more specific approach. Thus, it is expected to contribute to the promotion of better compliance with the therapeutic regimen, considering the importance of ART to ensure quality and life expectancy in this segment of the population.

Therefore, the nursing team has a relevant insertion in this process, from the construction of the therapeutic bond for guidance and encouragement in the face of possible obstacles encountered by patients. In this sense, the nursing consultation gains special importance, because it is a space it is possible to dialogue, to address the possible questions and diverse conditions capable of interfering in the use of ART.

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