

Adherence to antiretroviral therapy and its representations for people living with HIV/AIDS

Adesão à terapia antirretroviral e suas representações para pessoas vivendo com HIV/AIDS

Adhesión al tratamiento antirretroviral y sus representaciones por personas que viven con VIH/SIDA

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ABSTRACT

This study aimed to analyze the antiretroviral therapy adherence process and its social representation for people living with HIV/AIDS. This is a qualitative and descriptive study conducted on the Social Representation Theory. 30 people participated in an HIV/AIDS outpatient treatment in a public hospital in Rio de Janeiro. Data were collected through semi-structured interviews and subjected to thematic content analysis. It is evident that adverse events arising from the therapy, the fear of being seropositive revealed and the failure to realize themselves as sick result in the abandonment of therapy to the professional and family support showing it is essential that the person continues with the therapy. It is concluded that the adherence process shows a symbolic change process from the start of treatment until stabilization, which is expressed in attitudes and the image of the disease, virus and medications.

Keywords: Medication Adherence; Acquired immunodeficiency syndrome; Nursing.

RESUMO

Neste estudo objetivou-se analisar o processo de adesão à terapia antirretroviral e suas representações sociais para pessoas que vivem com HIV/AIDS. Trata-se de um estudo de natureza qualitativa e descritiva, elaborado à luz da Teoria das Representações Sociais. Participaram 30 pessoas em tratamento ambulatorial para HIV/AIDS em um hospital público do Rio de Janeiro. Os dados foram coletados por meio de entrevistas semiestruturadas e submetidos à análise de conteúdo temática. Observa-se que os eventos adversos decorrentes da terapia, o medo de ter a soropositividade revelada e o fato de não se perceber doente implicam o abandono da terapia, e que o amparo profissional e familiar é essencial para a que a pessoa prossiga com a terapia. Conclui-se que o processo de adesão evidencia um processo de mudanças simbólicas, do início do tratamento até sua estabilização, expresso em atitudes e imagens da doença, do vírus e dos medicamentos.

Palavras-chave: Adesão à medicação; Síndrome da Imunodeficiência Adquirida; Enfermagem.

RESUMEN

Este estudio objetivó analizar el proceso de adhesión a la terapia antirretroviral y sus representaciones sociales para personas que viven con VIH/SIDA. Es un estudio descriptivo, cualitativo, elaborado a la luz de las Representaciones Sociales. Participaron 30 personas en tratamiento ambulatorial para VIH/SIDA en un hospital público de Rio de Janeiro. Los datos fueron recolectados a través de entrevistas semiestruturadas y sometidos al análisis de contenido temático. Es evidente que los eventos adversos derivados de la terapia, el miedo de tener la seropositividad revelada y no darse cuenta de que es enfermo, resultan en abandono de la terapia, ya que el soporte profesional y familiar son esenciales para que la persona continúe el tratamiento. Se concluye que el proceso de adhesión muestra un proceso de cambios simbólicos, desde el inicio del tratamiento hasta su estabilización, expreso en actitudes e imágenes de la enfermedad, del virus y de los medicamentos.

Palabras-clave: Cumplimiento de la medicación; Síndrome de Inmunodeficiencia Adquirida; Enfermería.

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INTRODUCTION

To analyze the process of adherence to antiretroviral therapy considering the psychosocial construction of the epidemic through the social representations of patients with HIV / AIDS a brief historical review is necessary. Despite the reports observed in 1975, the first case of acute immune depression was described only in 1981 by CDC (Centers for Disease Control) in the United States, identified in 1982 its etiologic agent, the human immunodeficiency virus (HIV)¹. At first called WOG, acronym for "Wrath of God" or fury of God in Portuguese, the acquired immunodeficiency syndrome was the target of stigmatization and prejudice because of the fact that the first cases have been identified in groups male homosexuals, which had its sexual behavior judged and considered promiscuous by society¹.

In Brazil, studies show that in the period 1980 to June 2011 were registered 608,230 cases of AIDS. From 1980 to 2010, there were 241,469 deaths, having as root cause AIDS². Over these three decades there were numerous changes regarding the perception of the syndrome, mainly from 1996 with the introduction of combined antiretroviral (ARV) therapy. Therapy has led to a significant reduction in morbidity and mortality related to AIDS, going to be characterized as evolutionary and chronic, surpassing the vision of the beginning of the epidemic that was characterized as a disease that brought death as a certainty, in a short time³.

In this aspect it is worth noting that Brazil was one of the first countries to implement the universal distribution of medicines³. The results proved to be successful from the adoption of the concept of HAART (Highly Active Antiretroviral Therapy), which is the combination of protease inhibitors and reverse transcriptase, to be extremely effective in reducing plasma viral load of RNA-HIV-1 to undetectable levels⁴.

There is absolutely no doubt about the fact that HAART, although not a cure, making a slower course for the disease, the step that extends and promotes a better quality of life for the patient. However, studies have shown that the non-compliance occurs in some degree, in both rich and poor countries, and the average rate is 50%⁴. The non-adherence or inadequate adherence are the most frequent causes for the treatment failure, because the use of medicinal products in inappropriate doses or of irregular shape accelerates the process of selection of resistant viral strains, threatening the effectiveness of treatment at the individual level and leading to the spread of the virus resistance, at the collective level⁵.

The non-adherence is pointed out by the literature as an event determined by several factors, which can be grouped into factors related to the person under treatment, the

disease, the treatment, health services and social support⁶. Therefore, adherence to treatment with antiretroviral therapy shows itself as a complex process, highlighting the need to understand the subjective factors intrinsic to the person and their social group involved in the adherence process, in order to allow the formation of a real therapeutic alliance between client and caregiver.

By being little understood, the adherence shows itself at times as a tough process, generating wear both for the healthcare professional, as well as the person being cared for that many times choose to abandon the treatment by considers it an easy and less painful path. By studying the adherence process from the social representations of people living with HIV/AIDS, it becomes possible to identify how to manage their daily lives and thus identify possible factors influencing the vulnerability associated with this process.

Considering the biopsychosocial impact of the syndrome, as well as antiretroviral therapy, it has as objective to analyze the process of adherence to antiretroviral therapy and its social representations for people living with HIV/AIDS. This study becomes relevant by allowing the reflection on the psychosocial aspects involved in this process, making possible a better understanding of the events that lead to the rupture of this process.

THEORETIC REFERENTIAL

AIDS can be understood, as a social phenomenon possesses an immense stigmatizing load, in which the patient or virus carrier doubly experiences their suffering. On the one hand, we realized the physical suffering from a disease, which, even with the advances of science, still has no cure, while on the other; we see social suffering caused by the excludent look, intolerance, fear and prejudice towards people living with the virus⁷. Thus, AIDS is perceived as a disease that brings in addition to the prejudice, a series of uncertainties with respect to the future.

In this context, it is noted the inclusion of antiretroviral therapy, as of 1996, which brought with it a hope of prolonging life, giving the disease a chronic evolutive, potentially controlled character. However, adherence to treatment stands out among the greatest challenges of attention to people living with HIV/AIDS, a time that requires behavioral changes, dietary, the use of various medications for their whole life, besides the need, on the part of health care services, new arrangements and provision of specific activities designed to promote and ensure their adherence⁷.

Adherence to treatment is a collaborative process that facilitates the acceptance and integration of certain therapeutic regime into the daily lives of people in treatment, assuming their participation in decisions about them⁸. It

Consists in a process of negotiation in which it seeks the adequacy to the habits, individual needs, and which aims to strengthen the autonomy to self-care, transcending, thus, the simple ingestion of drugs⁹.

With regard to social representations theory, this has been widely used to explain the psychosocial problems of AIDS, a time which allows us to understand the meaning attributed to a phenomenon such as the sickening, directing the ducts of the subjects from the representations that they have built on the disease that they have. This happens because these social representations are inscribed in a human experience that has a series of meanings¹⁰. In other words, through the study of representations it becomes possible to understand the vision of the world that the HIV positive person constructs from their insertion into social groups. In addition to better understand the position taken and the behaviors adopted ahead to the adherence process, which allows the formation of a consistent link between the professional and the user.

This link, when established among the professionals involved in health care and the people who live with HIV/AIDS is of utmost importance to the adherence process. Since the consolidation of partnership between the professional and the patient in listening, feeling and thinking together allows the creation of solutions for improving the adhesion and the overcoming of numerous barriers that arise in everyday life⁸.

METHODOLOGY

This is a descriptive qualitative study conducted in the light of the social representations theory in the Social Psychology perspective, using the procedural approach, in which were explored the contents and processes of the formation of representations to the antiretroviral therapy adherence process.

The social representations themselves constitute as a way to understand and give meaning to what is strange or new. They are complex phenomena that are always active and active in social life. In its phenomenal wealth indicates various elements in its constitution, which are sometimes studied in isolation: pieces of information, cognitive, ideological, normative beliefs, values, attitudes, opinions, pictures etc. One can observe the social representations in daily life as they circulate in statements, they are recharged by the words, images and messages conveyed in the media, crystallized in conduits and intermediation, material or spatial¹¹.

For the realization of this study, 30 people were interviewed who live with HIV/AIDS, in the period from April to May 2009. The inclusion of the participants was given through preset criteria: being a studied specialized assistance service (SAE) user, older than 18 years, of both genders, in therapy with antiretroviral drugs, and who has received diagnosis less than 6 months prior, due to the time factor set as a determinant

in the development of social representations. The field of study was a municipal public hospital in the city of Rio de Janeiro, specialized and referenced for treatment of people with HIV/AIDS, being considered by the Ministry of Health as an SAE.

For the collection of data a semi-structured interview was used guided by a script topic, because they stimulate the research participants to talk more freely, allowing them to be the protagonists in this scenario and can reveal their ways of thinking, values, feelings, as well as the objective and subjective factors that motivate or hinder their adherence to therapy. For such, were raised questions concerning how was the start of therapy, and who helped most during this process and what actions were taken with the difficulties imposed by therapy.

The research was approved by the Research Ethics Committee of the Municipal Secretary of Health (CEP SMS-RJ) being its approval protocol 200/08. The interviews were recorded with the consent of the interviewees and signed the free and informed consent term according to resolution 196/96. It is worth noting that the research relied on volunteers who agreed to participate after being informed about the objectives of the survey and assured about the confidential nature of their discourse.

After collections, transcripts were made of the interviews, in order to allow a thorough analysis of each statement and their transversal elements, seeking to identify common aspects with patients that interfere in the adherence process. For this purpose, the thematic-categorical content analysis was used^{12,13}. The content analysis technique allows access of various explicit content or not present in a text, but to do this requires some steps, such as: pre-analysis, exploration of the material or encoding, treatment of results, inference and interpretation¹². For the realization of this technique a systematization¹³ was employed in which, in principle, carried out a thorough initial reading of the text in order to allowing to be impressed by the elements present in the text, but without attachment to specific elements in the reading. After reading, the objectives of the analysis were defined as well as some hypotheses on the examined object. It was started, then the pre-analysis which were identified reporting units (RU) as defined clippings meanings expressed in the text by partial or complete sentences and / or paragraphs, as well as characters and events that are important facts for the object under study.

The testimonies of the participants were identified in the text according to the number given to the subject during the interview (subject 01, subject 02, etc.).

PRESENTATION AND DISCUSSION OF RESULTS

Of the 30 respondents, 76.7% are concentrated in the age group of 30 to 49 years and in their majority are married, living with a partner or have a stable union (50%). Thus, the

greater part lives with family (76.7%) and has schooling up to complete high school education (36.7%), earn up to 4 minimum wages (n = 23 or 76.6%). Predominated in the study people living with HIV for less than 11 years (69.6%), heterosexual (63.3%), predominantly catholic (44%) followed by Evangelical (36%).

Regarding the analysis of the discursive data results, we obtained 380 RU and 36 units of meaning. These units were distributed into three categories that represent 100% of the analyzed *corpus*. The three categories were named as Factors that hinder the process of adherence to antiretroviral therapy; Elements that facilitate the process of adherence to the antiretroviral therapy; Change and appreciation of life in the adaptation process to antiretroviral drugs. For this text, these categories were addressed separately, analyzing each one of them and stressing their quantitative representation.

Category 1 - Factors that hinder the adherence process to antiretroviral therapy

This category, the largest of the analysis, involves 186 RU and 19 meaning units, which is equivalent to 48.9% of the *corpus* of analysis. It identified the reasons that lead patients to abandon the treatment or not adhering properly. The main topics/units of meaning that have been part of this analysis were: adverse effects very difficult to adherence, returning to take medication when they fall ill by fear of death, need to hide from family, friends and work colleagues and stop to take when they feel well, think they are cured.

Within this category, we found a negative attitude present in the social representation of antiretroviral therapy expressing the difficulty imposed by the adverse effects of antiretroviral drugs. This makes the treatment itself aversive, causing its abandonment seem an easier alternative and relieving as the following RU:

Figure 1. Table summary of the construction of categories in content analysis, Rio de Janeiro, 2012

Topics/significance units	Nº RU/ Topic	% RU/ Topic	Categories	Nº RU/ Category	% RU/ Category
Quantity of Pills	17	4.5	Factors that hinder the process of adherence to antiretroviral therapy	186	48.9
Injectable Administration	5	1.3			
Frequency of medications	1	0.3			
Dependence on medication (mandatory)	21	5.5			
Adverse effects that greatly hinder adherence	36	9.5			
Lack of love for life, disinterest, suicidal thoughts.	22	5.8			
Take wrong due to ignorance	3	0.8			
Go back to taking medication when they get sick, for fear of death	26	6.8			
Constant visits to the hospital for examinations	2	0.5			
They believe that therapy offers risks, that can kill	2	0.5			
Do not take or take improperly when they want to escape the routine	4	1.1			
Need to hide from family, friends or colleagues at work	16	4.2			
Do not accept the treatment denial, rejection	7	1.8			
Indifference, laziness, sloppiness with the treatment	6	1.6			
The treatment does not match their expectations	2	0.5			
Do not adhere for lack of information (ignorance)	4	1.1			
The beginning is painful, suffering	6	1.6			
Disinterest by the professional	2	0.5			
Stop taking when they feel well and cured	4	1.1			

Continued Figure 1.

Topics/significance units	Nº RU/ Topic	% RU/ Topic	Categories	Nº RU/ Category	% RU/ Category
Seek take at the right times	19	5.0			
Free Distribution	4	1.1			
Care with the diet	18	4.7			
Spiritual Support	8	2.1			
Support from family	13	3.4			
Support, guidance and professional interest	37	9.7	Elements that facilitate the adherence process to antiretroviral therapy	123	32.3
Recognize lectures and posters as strategies	9	2.4			
Aware of NGOs and support groups, but did not attend due to lack of time	3	0.8			
Seek affection, love	2	0.5			
Looking for taking the medication correctly to avoid complications	10	2.6			
Don't hide	7	1.8			
Adaptation to the medication in daily routine	10	2.6			
They had No difficulties or problems during the adaptation	25	6.6	Change and appreciation of life in the adaptation process to antiretroviral drugs.	71	18.6
After the adaptation everything improves	11	2.9			
Change of habits	5	1.3			
Desire to prolong life	5	1.3			
Cling to life, want to live longer	8	2.1			
Total	380	100		380	100

Sometimes, the people, in the case of many who suffer with the effects, then, sometimes, do so badly, so badly, that they prefer not to take, sometimes the person says: ah, I'm already bad even, I'm bad (subject 21). Through the reactions. Of vomiting, diarrhea, dizziness, one thing, which if you don't persevere, you quit. That is tough... (Subject 07).

In addition to the vomiting, diarrhea, headache and sleepiness, there are body changes, such as lipodystrophy, as hinderers to the adherence process and that interfere mainly in self-esteem of people who live with HIV/AIDS. Some changes are assigned by subject the amount of medicines that must be ingested, this being another complicating factor, also, as RU below:

I don't take the medication because I'm diabetic, because of lipodystrophy, I'll stick with the ugly face, the ugly face and the side effects. Some side effects are bizarre, really... (Subject 21). Every time I go get the drugs I throw all the labels in the trash, just take

the medications, the box and everything I throw away because if you read and becomes aware you will read and understand something because the same medicine that makes you well it will do away with your kidneys. It is not out of malice, it is the amount of drugs... (Subject 01).

The lipodystrophy, which expresses a dimension of imagery representation of antiretroviral therapy, brings a new stigma in relation to disease, because it fosters the discovery of the condition of seropositivity by third parties and impact on self-image and sexuality, which may influence the quality of the adherence and lead to the abandonment of treatment⁸.

It is also observed that taking the medication involves perceiving it or feel sick, which leads to two problems: the first is the fact that the patient only seek help when they are ill, and the second is that after you feel good or "cured", abandons the treatment again. Another complicating factor is the dependence of the lifetime maintenance to the drug, leading the client and feel compelled to take the drug, since them not taking; it equates to die according to the RU below:

When the disease attacks... when it manifests itself and I begin to feel something, here comes a call to the doctor... When you're okay, you disappear again... (Subject 15). Only when undetected, what will happen? I stayed without taking medication, which, incidentally, stimulates it. Then we have to do our part (subject 16). You have to take it; you are obliged to take it. You have to take, if not you die (subject 01).

The introduction of antiretroviral therapy gave people with HIV/AIDS a new perspective, by modifying the course of the disease and bringing a significant improvement in quality of life, especially after the introduction of the concept of HAART, which consists in the combination of different antiviral drugs.

However, therapy is associated with fear and loneliness by objectifying the situation of seropositivity, since in many cases, the drugs are the only evidence that the person is HIV positive. The removal of the labels or the disposal of bottles ends up being a resource used by clients as a way to avoid the discovery of seropositivity by third parties⁸.

In this sense, the participants of this study also reveal this fear of discovery of diagnosis and social isolation, which encompass the conditions of transport and storage of medicines which require to be stored in refrigerators:

When I get home I am obliged to take the label of the medication, everything that refers to AIDS I remove, because they will read and will ask. My children, so they don't find out I remove the labels (subject 5). The fear of you be discovered, if it is a person who does not account for the family, as it is that you will save the medicines in the refrigerator, if in your home nobody knows? How are you going to take the drug to work, if no one at work knows? On the other hand, will you lie to a girlfriend or a boyfriend, if you have never told them? The fear of loneliness is to be... it is to be alone. I think that the person does not adhere to treatment, because they'll expose them self, one day a pill may drop on the floor, or just make a mistake and leave them out, or say something (subject 29).

An important component of the analyzed discursive structure as to the reasons for non-adherence to medication is the lack of will to live and the meaning of life, as well as lack of self-esteem and fear of not surviving. These representational elements derived mainly from imagery of death present in the social representation of AIDS:

Not if you like it, because if you're sick and have to take the medication, that medication will prolong your life, and you do not want to take it is because you do not like

yourself. You want to kill yourself (subject 28). I think that it is because these people are afraid, because they do not believe that he will survive, thinks that the life of them ended, and then prefers to end it faster.

This is corroborated by another study, which shows that the representation of death implies a negative attitude toward the disease, to the extent that people with HIV/AIDS consider death as something inevitable and leave to find a meaning for drug adherence¹⁴.

It becomes evident in this category that the patient cannot and should not be the sole agent of the adherence process, since there is a social network, such as family, friends and professionals who have an influence on the decision to take the medication or not. It emphasizes, therefore, the need for acceptance of the person with HIV/AIDS by part of the healthcare team, as well as the development of a joint action between the professional team and the person carefully, paying special attention to the adverse effects and looking for devising strategies to improve adherence.

Category 2 - Elements that facilitate the adherence process to antiretroviral therapy

This category is comprised of 123 RUs and 8 meaning units, equivalent to 32.3% of the analyzed data. It addresses the elements and agents that contribute positively to the antiretroviral treatment adaptation process. These agents involve the family, health professional and the subject them self. As the main meaning units, it has the: looking at the right times, take care with food, support from family, support, guidance and interest of professionals.

In this category, therefore, identifies the positive attitude of the social representation of antiretroviral therapy and care with time as the main form of adjustment of routine treatment, a concern taken by the subject. The understanding of the importance of schedules in effectiveness of treatment is also clear:

You have to be aware at the time. Before you leave for the day, you have to schedule it because you can't forget the medication (subject 3). The interval doesn't make a lot difference because in time the viruses will resist the medicine. (Subject 3). I take it at the right times, avoiding going off schedule to not have future problems. (Subject 12). I cannot be too late; I cannot stop taking the medicine... (Subject 10).

The family is configured as a support network of extreme importance to carry forward the adherence to medication treatment. It is observed that importance of family nucleus as a strong reason, mainly in cases of abandonment, for the resumption of the treatment, as in the RU below:

Oh, it is love from the family. [...] What really counts are your relatives. The love of them, encouraging them, the love that a person has for life, and the desire to live (subject 18). I returned to treatment because of my children, it was not because of me. I think so... I already have lived up to now, for me both makes being here or not being here, I returned more because of my children (subject 4).

People who can mobilize resources both individual and social experience to new situations posed by ARVs adapt better to their new condition. In this context, the family constitutes itself as an agent that supports the adherence to antiretroviral therapy and, therefore, the caregivers must take into account the family core of the person in treatment, seeking identifies them and insert them in this process¹⁵.

Another social actor referred involved in the adherence process to drug therapy is the health professional, especially doctors and nurses, who are seen as enhancers, already seeking follow the routine of the person cared for, as testimony to the following:

Who encourages me? At the time now, it's a doctor [...], because when the baby is born who will move on to consult me is the doctor [...], my doctor, she encourages me too (Subject 16). Before you get to the doctors, the nurses themselves advise... Give advice, looking to see schedules, look for the everyday life of the person, the person's routine (subject 3).

In this sense, health services are of paramount importance to the adherence, as by healthcare professionals enable dialog, communication, allowing a relationship where the negotiation, places them as possible. These services have trace strategies such as case studies, interdisciplinary workshops and groups of adherence, which has as objective to improve adherence to treatment by receiving the patient and making them the main subject of this change process¹⁶.

The incentives on the part of the family and the professionals show up as essential factors for treatment adherence. When the patient perceives the conviction that health professionals have on a given therapeutic agent, they tend to internalize this conviction, which contributes greatly to their adherence⁹.

Category 3 - Change and appreciation of life in the adaptation process to antiretroviral drugs

The initiation of ARV therapy, although troubled, is also marked by hope deposited in the treatment. This hope, along with the social support and the strategies developed by the health team, allows the seropositive person to overcome the adversities and proceed with treatment⁸.

With 58 RUs and 15.3% of the analysis *corpus*, this category is dedicated to describe the daily life of people with HIV/AIDS after adaptation to antiretroviral drugs. In this category were addressed four meaning units: not hiding, adaptation of medication daily routine, after adaptation and everything improves, change of habits, clinging to life and want to live longer.

After the adaptation, notes to consolidation of a routine in which the person who lives with HIV/AIDS can tailor the antiretroviral therapy to their life. This adjustment summed the reduction or absence of side effects resulting from the adaptation of the body to the drug leads to a change in perception about the therapy. This will no longer have a representation negative, going to be seen as a source of well-being or as something normal in everyday life:

The times noon and midnight are the times that I adjusted my work routine, my personal routine, that are practical and when I'm on the street I have a plastic box... that for years I bring my medications (subject 29). Today, is two years that I have taken it every day, I'm fine, however, after I started to take the medicine, I even feel better (subject 05). In the beginning, it was difficult... it was very difficult. The first week until I adapted to the medication, my body adapted I suffered greatly. Because I was very nauseous, many headaches, pain in my body... However, after a week it all disappeared, vanished and I returned to having a normal life (subject 17). [...] I was learning to live with the reactions that the medicine gave me, I was that way once a month and a month and a half and then not anymore, I remained normal (subject 30).

In this respect, the construction of the habit of taking the medication, along with the possibility of changes in the combination of medicines, assists the acceptance of ARV therapy. Confidence in treatment is reinforced when the asymptomatic period is prolonged, because for people with HIV/AIDS, the long periods without symptoms demonstrate the effectiveness of the antiretroviral drugs¹⁷.

The adherence process, by its turn, ends up being seen as a form of learning in which it is necessary to acquire self-knowledge, passing to respect the limitations imposed by the disease and to live in a more healthy way. Thus, the social representations of antiretroviral therapy assume a practical character, which implies a change of old habits, according to the statements:

I avoid drinking, avoiding lost nights of sleep, speaking of the importance of rest in the person's life, and many things, being that the person if it is the case I will stay

away from alcohol, remembering the medication times, showing how it is that if you take them all, saying the type of medicines (subject 19).

The membership can be seen as a collaborative process and not in care unidirectional, implying the correspondence of the professional and client. Initially, the care practice must start from the person with the virus being that this is the main change agent. Notes in this respect that the assisted person understands the need for self-knowledge, as well as the self-care, as in the RUs below:

Either live having, being HIV positive, you have to take seriously, have to respect your body, you have to know your body. Many people live seeing the body, but ignore their own body, then this is very much reinforced, not being scared, don't believe in everything you hear, do not follow these rumors and fashions, and always protect yourself (subject 29).

In this respect, people who believe in their ability to cope or deal with the circumstances that might prevent them from achieving health behavior, both in terms of preventive treatment, show with a better adherence to treatment regimens, unlike people who perceive themselves incapable or without skills to handle the adversity from the treatment¹⁸.

As a way to get a sense for whether live front to the disease, emerges from the search for what is sacred in life. It was observed that the faith and waiting in the divine as a way of dealing with the fact of not being able to modify their own reality, depositing as well, the hope of a change of reality on a greater being:

Or people begin to advise, to tell them it is not so, or sometimes a person goes to church and talks: now God will help me. Therefore, you have to have some point of support for their return... (Subject 14) what helps me a lot is the faith that I know is very great (subject 13) This feeds our spirit, this faith as well, I am already healed... I am healed... (Subject 13).

Thus, religion presents itself as an important motivational factor, given that the search for spirituality is configured as "support base for which the people live their lives and even to change their ways to lead their life"^{15:735}.

Despite the introduction of antiretroviral therapy, AIDS is still very marked by the representation of death. Therefore, attachment to life is an important motivational factor for medication adherence:

So In Fact, they will return, and what will be their encouragement? They will want to live, and they want to live she has to identify a target and have to start taking the drugs (subject 12). For those who have the goal of living a little more, or live everything that they need to live, I think it is important (subject 09). It is always interesting living a little more... (Subject 09).

One can perceive in this category that the adherence process is as a process of learning in which the person experiences the experience of seropositivity and from this win forces for mobilization of changes, taking a position in relation to the disease and life¹⁵. We see that to mobilize resources for coping with the situation, such as the adequacy of treatment the daily routine and the perseverance to continue even in the face of adverse effects, it becomes possible to give continuity to the treatment, the attitude before the antiretroviral therapy is positive.

CONCLUSION

Upon the results obtained, it was concluded that the adherence process is a multifactorial event and extremely influenced by an interconnected network of several issues that pervades the living conditions, such as the work and interpersonal relationships. This process can be overwhelmed by factors related to the person with HIV, the disease, the treatment, and to the environment surrounding the client.

This study shows that the early use of ARV is marked by a representation strictly negative, expressed in the image of social isolation, fear of experiencing the prejudice hindering the adherence process. The family nucleus shows itself as agent motivator of this process, especially when this nucleus involves dependents of the person in treatment, such as the children. However, it was observed that when there is no possibility of revelation of the state of seropositivity to the family, this process becomes more difficult, because the person with HIV/AIDS tends to use the for fear of being recognized as HIV positive

It is evident that the fear of being recognized is related to factors such as the discovery of ARVs by third parties, mainly family and the perception by others regarding side effects expressed mainly in image of lipodystrophy. This fear determines actions of concealment of the medication as a form of denial of the disease, such as the disposal of lables, boxes and, in some cases, even of their own medicines.

In spite of the person with HIV/AIDS be seen as protagonist in the adherence process, it was observed that the customer cannot act alone during this process, highlighting the professional host as a strong motivating factor, to the extent that develops in "adherent" confidence in treatment. It can be noticed, as well, the need for an active listening, in

which the professional should welcome the conversations of the person with HIV, without expressing judgment of value to what is being said, thereby allowing a person to develop confidence in professional and express their doubts, anxieties, fears and expectations. The need for practitioners is highlight to observe and identify the presence of possible factors that may be hindering or affecting medication adherence self-confidence of the clients

The representations of the adherence process demonstrate the development of a process of change symbolic since the start of the treatment until its stabilization, which is expressed in not only attitudes, but also the representative images of the disease, the virus and medicines. This process is evidenced when the seropositive person can overcome the difficulties imposed by the initial treatment, comes to understand this process as a period of learning and face the antiretroviral therapy as a new motivation for life, assuming a positive attitude towards it.

It is noted that the study had a limited number of subjects and was conducted in a single field that accompanies people who are in use of antiretroviral therapy, it is not possible to reach people who did not adhere to therapy and reveal the process of adaptation to antiretroviral therapy. It Highlights the need for new more comprehensive studies, which specifically address this process, being that this is still a great challenge and that they committed to continuity of therapy.

REFERENCES

1. Campos MS, Coelho MTAD. A AIDS e o discurso homofóbico da indústria cinematográfica hollywoodiana. Anais eletrônicos do Seminário Internacional Fazendo Gênero 9: Diásporas, Diversidades, Deslocamentos; 2010 ago 23-26. Florianópolis (SC), Brasil. Florianópolis(SC): UFSC; 2010. p. 1-7. Disponível em: http://www.fazendogenero.ufsc.br/9/resources/anais/1278272053_ARQUIVO_AAids.pdf
2. Ministério da Saúde (BR). Boletim Epidemiológico: AIDS/DST. Brasília(DF): MS; 2011.
3. Cardoso GP, Arruda A. As representações sociais da soropositividade e sua relação com a observância terapêutica. *Cienc. saude colet.* 2004;10(1):151-62.
4. Colombrini MRC, Coleta MFD, Lopes MHBM. Fatores de risco para a não adesão ao tratamento com terapia antiretroviral altamente eficaz. *Rev Esc Enferm USP.* 2008;42(3):490-5.
5. Ministério da Saúde (BR). Guia de tratamento: recomendações para terapia antiretroviral em adultos e adolescentes infectados pelo HIV. Brasília(DF): MS; 2006.
6. Brawley LR, Culos-Reed SN. Studying Adherence to Therapeutic Regimens: Overview, Theories, Recommendations. *Control Clin Trials.* 2000 Oct;21(5 Suppl):156-63.
7. Barbará A, Sachetti VAR, Crepaldi MA. Contribuições das representações sociais ao estudo da AIDS. *Interação.* 2005 jul/dez;9(2):331-9.
8. Ministério da Saúde (BR). Manual de adesão ao tratamento para pessoas vivendo com HIV e AIDS. Brasília(DF): MS; 2008.
9. Ministério da Saúde (BR). Diretrizes para o fortalecimento das ações de adesão ao tratamento para pessoas que vivem com HIV/AIDS. Brasília(DF): MS; 2007.
10. Herzlich C. A problemática da representação e sua utilidade no campo da doença. *Physis [online].* 2005;15(suppl):57-70 Disponível em: <http://www.scielo.br/pdf/physis/v15s0/v15s0a04.pdf>.
11. Jodelet D. Représentations sociales: un domaine en expansion. In: Jodelet D, organizadora. *Les représentations sociales.* Paris (FRA): PUF; 1989. p. 31-61.
12. Bardin L. *Análise de conteúdo.* Lisboa(POR): edições 70; 2010.
13. Oliveira DC. Análise de conteúdo temático-categorial: uma proposta de sistematização. *Rev. enferm. UERJ.* 2008;16(4):569-76.
14. Gomes AMT, Oliveira DC, Santos EI, Santo CCE, Valois BRG, Pontes APM. As facetas do convívio com o HIV: formas de relações sociais e representações sociais da AIDS para pessoas soropositivas hospitalizadas. *Esc. Anna Nery.* 2012 jan/mar;16(1):111-20.
15. Teixeira MG, Silva GA. A representação do portador do vírus da imunodeficiência humana sobre o tratamento com os anti-retrovirais. *Rev Esc Enferm USP [online].* 2008;42(4):729-36. Disponível em: <http://www.scielo.br/pdf/reeusp/v42n4/v42n4a15.pdf>.
16. Narciso MAS, Paulilo MAS. Adesão e AIDS: alguns fatores intervenientes. *Serv. soc. rev.* 2001 jul/dez;4(1):27-43.
17. Torres TL, Camargo BV. Representações sociais da Aids e da Terapia Anti-retroviral para pessoas vivendo com HIV. *Psicologia: teoria e pratica.* 2008;10(1):64-78.
18. Seidl EMF, Melchiades A, Farias V, Brito A. Pessoas vivendo com HIV/AIDS: variáveis associadas à adesão ao tratamento antirretroviral. *Cad. Saude Publica.* 2007 out;23(10):2305-16.