ORIGINAL ARTICLE

The representation of hiv carriers about antiretroviral treatment*

A REPRESENTAÇÃO DO PORTADOR DO VÍRUS DA IMUNODEFICIÊNCIA HUMANA SOBRE O TRATAMENTO COM OS ANTI-RETROVIRAIS

LA REPRESENTACIÓN DEL PORTADOR DE VIRUS DE INMUNODEFICIENCIA HUMANA SOBRE EL TRATAMIENTO ANTIRRETROVIRAL

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ABSTRACT

Having the perception of the HIV/AIDS carriers about compliance with antiretroviral medication, this qualitative study aimed at comprehending the social representations of the HIV/AIDS carriers about the drug therapy; analyzing the relation between the perception of the HIV/AIDS carriers about the drug therapy and their motivation to comply with the treatment. The research subjects were nine users, hospitalized in an infectious-contagious unit of a school hospital in the city of Juiz de Fora. Data collection occurred with semi-structured interviews. The analysis categories allowed to discuss the several aspects of antiretroviral compliance, starting from the representations elaborated by the subjects who undergo the treatment, who, using dialogue as a mediator, talk about the hindering aspects and the motivations for managing the treatment.

RESUMO

Tendo como objeto de investigação a percepção dos portadores do HIV/AIDS sobre a adesão à terapêutica com medicamentos anti-retrovirais, este estudo de abordagem qualitativa teve como objetivos: conhecer as representações sociais dos portadores do HIV/AIDS sobre a terapêutica medicamentosa e analisar a relação entre a percepção do portador do HIV/AIDS sobre a terapêutica medicamentosa e a motivação para aderir ao tratamento. Os sujeitos do estudo foram nove usuários, internados na unidade de doenças infecciosas de um hospital de ensino na cidade de Juiz de Fora. Os dados foram colhidos através de entrevista semi-estruturada. A categoria de análise permitiu discutir as diversas facetas da adesão aos anti-retrovirais, partindo das representações elaboradas pelos sujeitos que fazem o tratamento, os quais, tomando como mediação o diálogo, falam dos aspectos dificultadores e as motivações para a gestão do tratamento.

RESUMEN

Estudio cualitativo que tuvo por objeto de estudio la percepción de los portadores de VIH/SIDA sobre el seguimiento medicamentosos con antirretrovirales. Objetivos: conocer las representaciones sociales de los portadores de VIH/SIDA sobre el tratamiento medicamentoso y la motivación para continuar con el mismo. Los sujetos del estudio fueron nueve usuarios, internados en el servicio de enfermedades infecciosas de un hospital de enseñanza de la ciudad de Juiz de Fora. Los datos fueron obtenidos a través de entrevista semiestructurada. La categoría de análisis permitió discutir las diversas etapas relacionadas al uso continuo de antirretroviales, en base a las representaciones construidas por los sujetos en estudio; utilizando el diálogo expresaron las dificultades y motivaciones para la gestión en el tratamiento

KEY WORDS

Acquired immunodeficiency syndrome/ therapy.
Patient participation.
Attitude to health.

DESCRITORES

Síndrome de imunodeficiência adquirida/ terapia.
Participação do paciente.
Atitude frente a saúde.

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Participación del paciente.
Actitud frente a la salud.

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INTRODUCTION

The outbreak of a new disease, in the early 1980s, caused significant changes, both in healthcare and other areas, because its origin was associated with the sexual behavior of the afflicted people. It was identified as a syndrome, known worldwide by the English acronym AIDS (Acquired Immunodeficiency Syndrome). The AIDS onset dissolved the opposition between past epidemics and modern diseases.

Opposed to what was believed for decades, the age of contagious diseases, and especially viral diseases, probably is not over(1).

Published data show that there are about 39.5 million people living with HIV in the world, most of whom live in third-world countries, and that a small number of them uses anti-retroviral drugs. From 1980 to 2007, 474,273 cases were registered in Brazil. About 192,709 people have died since the beginning of the epidemic, and over 70% of the virus carriers, either sick or not, currently use anti-retrovirals(2).

> The term *compliance* with the treatment should be seen as a joint activity, where the service user not only obeys the medical orientations, but understands, agrees and follows the prescription established by the physician.

Knowledge about the virus dynamics and its implications for the life of carriers, in consonance with discoveries in the drug field, allow for an optimistic perspective regarding coping strategies. The development of an anti-retroviral therapy is one of the important factors in the history of facing health problems nowadays. Although it does not represent a cure, it is a therapy capable of changing the progress of the disease. However, it is a complex evolution that requires users' understanding and acceptance, and also therapeutic recommendations that reflect in the dynamics of everyday life.

After being informed of their seropositive status, patients in countries like Brazil are given the option to enroll in a monitoring program. Surpassing the common view at the onset of the epidemic, which characterized AIDS as a disease that entailed a certain death in a brief length of time, the inclusion of anti-retrovirals in the treatment brought new possibilities and perspectives. However, despite all efforts to assure that everyone will receive the medication they need, it is common to find patients who do not follow the therapy. This situation causes discomfort in healthcare professionals, who often do not understand what lies behind non-compliance.

Studies performed by several researchers in the USA and Europe have shown a significant reduction in the amount of deaths secondary to AIDS and the occurrence of opportunist infections(3). The use of anti-retroviral therapy has shown positive results in all countries where HIV-infected individuals have had access to these drugs and complied with the treatment program.

The term *compliance* with the treatment should be seen as a joint activity, where the service user not only obeys the medical orientations, but understands, agrees and follows the prescription established by the physician. It also means that there should be a *therapeutic alliance* between the physician and the client, where not only the specific responsibility of each part in the process is recognized, but also the responsibility of all people involved (either directly or indirectly) in the treatment(4). Therefore, the enormous investment in research and development of anti-retroviral drugs, as well as the technology necessary for monitoring treatment efficacy may be lost if strategies aiming to increase HIV/AIDS carriers' treatment compliance are not developed(4).

In spite of therapeutic advances, it is estimated that between 10 and 20% of the clients who start treatment cannot suppress the viremia adequately after a few months of therapy (primary virologic failure), and from 20 to 50% of those with good initial response will have a virologic failure after one year of treatment (secondary virologic failure), with a progressively lower rate of virologic responses in subsequent treatments. Therapeutic failure, especially due to drug resistance, is an expected phenomenon, and a growing number of clients no longer have anti-retroviral drug options. Inadequate compliance is the most frequent cause of treatment failure, since the use of these drugs in sub-optimal doses or done irregularly accelerates the selection process of resistant viral strains(5).

The use of anti-retrovirals to treat AIDS brought significant improvements in quality of life for HIV carriers, contributing for AIDS to have characteristics of a chronic disease. Despite the great benefits granted by this therapy, however, there are still difficulties to be overcome – including the carrier's compliance with the treatment.

Several factors influence everyday life of HIV carriers undergoing the therapy. The patient is the only person able to really characterize such influences in the process of managing the treatment during its existence, while a cure is not discovered. Hence, emphasis should be given to the adoption of measures that can minimize the individuals' vulnerability to the disease, taking the patients' motivation and doubts as a reference(4).

The several peculiarities guiding compliance with anti-retrovirals were the motivation for this research, which aimed at investigating the perception of HIV/AIDS carriers about compliance with drug therapy. The following objectives were elaborated:

- Getting to know the social representations of HIV/AIDS carriers about the drug therapy;
- Analyzing the relation between the HIV/AIDS carrier's perception about the drug therapy and the motivation to comply.

METHOD

The Social Representations Theory

Using the assumptions of social representations as a base, it is expected that this study, by accessing the representations of HIV carriers about how they manage to deal with this health problem daily, reveals the aspects that influence their vulnerability in the disease process. HIV and its repercussions in the organism are a privileged space for the elaboration of representations, a space often assured by uncertainties related to the dynamics of the epidemic.

Social representations are complex phenomena, always active and in progress in social life and, in their own richness as a phenomenon, we found several elements: informative, cognitive, ideological, normative, beliefs, values, attitudes, opinions, images, etc, which are always organized under the appearance of knowledge about the state of reality. The representations express those (individuals or groups) that make them and specifically define the represented object. These definitions, shared by members of a single group, build a consensual vision of reality for this group. Even though this vision may conflict with the vision of other groups, it is a guide for daily actions and exchanges(6).

HIV/AIDS carriers bring contributions through their representations, so that we can think about the problem under investigation, because their representations form a lifelong conception and guide their actions towards coping with the consequent HIV-vulnerability and disease.

The methodological stages of the study

This study is grounded on the qualitative approach. This form was shown to be the most adequate, since we worked with individuals living with a disease that is still stigmatizing, which needs treatment marred by doubts about its efficiency and difficult to accept, often for those who have it and their peers. Therefore, it is a theme that involves conceptions, opinions, beliefs and attitudes regarding the patients' life and treatment.

By choosing this course, the intention was to allow the subjects living with the condition of being HIV-seropositive, sick or not, to feel as the protagonists in this scenario and, in addition, reveal the nuances of acceptance or non-acceptance of the therapy offered by the healthcare services.

Objective qualitative research, in general, seeks to clarify a given situation so that the researchers can become aware of the problems and conditions that generate them, in order to elaborate means and strategies to solve them(7).

The study subjects were nine HIV carriers who had started treatment with anti-retroviral drugs. They were hospitalized in the nursing wards for infectious and parasitic diseases at a public hospital in Juiz de Fora. During the time when the interviews were held (July to September), there were 19 hospitalizations at the male and female infectious disease wards. Only hospitalized patients were included in the study, because the outpatient clinic of the institution was undergoing renovations at the time of data collection. However, it is important to note that all study subjects were being monitored at the outpatient clinic of the institution analyzed by this study.

Subjects were named with pseudonyms so as to guarantee their anonymity. According to regulation 196/96(8) about research involving human beings, established by the Ministry of Health, the study was submitted to the Ethics Committee at Universidade Federal de Juiz de Fora, protocol number 3900752004. In addition to guaranteeing anonymity, the study subjects were told that their participation could be ended at any moment if so they wished, without any damage caused.

Data were collected with semi-structured interviews. This is a technique which allows the interviewee to talk freely about the topic. The interviewees were informed about the nature of the research, its goals and justifications, and then they could decide whether or not to take part. Having this information, the term of consent was signed, where the subject authorized the interview to be recorded and published in the future.

Later, the transcribed material obtained through interviewing allowed for the definition of the theme of analysis: compliance with drug treatment in its challenging aspects and motivation for managing the treatment. The analysis is supported by authors who discuss the dynamics of representations about anti-retroviral treatment.

RESULTS AND DISCUSSION

The category extracted from the data, which the analysis will be directed at, was named compliance with drug treatment: challenging aspects and motivation for managing the treatment.

With the start of the use of anti-retrovirals in AIDS treatment, in 1985, significant improvements were noticed in the quality of life of the carriers. The longer survival of HIV/AIDS seropositive people, after using anti-retroviral drugs, has been demonstrated in several studies. The reduced incidence of associated diseases constitutes another equally important result of the combined therapy and primary prophylaxis with anti-retrovirals(9).

The main goal of anti-retroviral therapy is to delay the progression of immunodeficiency, or to restore immunity as much as possible, increasing the length and quality of life for the infected person(5). This is shown in the following testimony, on how the patient can perceive the benefits of the anti-retroviral drugs when the treatment is done correctly:

> the good thing is to do it right, because the person can live well, ok (Friendship).

However, although HIV carriers acknowledge the great benefits granted by this therapy, there are still several difficulties to be overcome. One of them is the client's compliance with the drug treatment.

The presence of HIV or AIDS is represented by a group of symptoms that characterize the disease and somehow indicate the need to seek a healthcare service, becoming an undesirable event that threatens and sometimes radically changes the lives of infected people(10).

Several factors are directly associated to compliance. The main reasons why HIV-seropositive patients abandon their anti-retroviral treatment include: side effects, affective losses, conflicts between taking medication and lifestyles and the imposition of treatment by the physician(11).

The prescribed therapeutic scheme, including the amount of drugs, its forms and times, is associated to non-compliance, even when the drugs are provided. This is one of the main factors related to drugs that interfere in treatment with anti-retrovirals, because the therapeutic schemes are usually complex and demand great commitment from the clients, who needs to adapt their eating habits, schedules and daily routine to follow the treatment. The testimony mentions the difficulties of having to take a large amount of drugs as a challenging aspect of compliance:

> I think that's six at a time. That's too many pills […] it's really difficult (Tranquility).

In some cases, the way of easing the regular use of drugs becomes impossible when the carrier's job is considered:

> I have a job. Sometimes I'm busy and I can't take the pills. Then, I take them later. If the boss needs something, I can't say I have to go and take my medicine (Tranquility).

Job responsibilities and financial needs are greater than healthcare needs. This fact can be asserted by the following testimony:

> At that time, I came here and talked to the doctor, and I was supposed to come back again, but, since I'm a driver, it can't stop, and it took me too long to come back. I couldn't stand the drugs any more and needed to travel […] At first I was resistant, because they made me very sick, I couldn't even work, so I stopped […] at the time, it was difficult to work and do the treatment (Love).

It is interesting to consider that the occurrence of a health problem produces limitations that frequently reflect in the development of professional activities and, consequently, in people's survival. In this perspective, the disease represents incapacity for work, not only damage to the biological body. Often, the individuals delay the search for a healthcare service to perform the diagnosis or treatment, in an attempt to avoid worsening their life conditions(12).

If the carrier has to choose between eating adequately and allowing the whole family to eat well, the second option is chosen. The lack of financial resources, even to acquire food, since treatment requires adequate dieting that can minimize the side effects, is a discouraging factor. Friendship's testimony shows this concern:

> I wasn't eating right, no… […] I've got anemia, so that helps the drugs attack me […] Sometimes I don't have money to eat well […] I have four children (Friendship).

Another aspect that causes difficulties for non-compliance is the routine imposed to follow the therapy:

> I also can't drink, I can't relax too much on the streets, because I have to take my medicine (Tranquility).

This perception about changes in the daily routine is also revealed in the following statement:

> The drugs hamper me, right? I can't go out […] So how do I do it? The meds I take need to be stored in the refrigerator (Hope).

Subjects using anti-retrovirals constantly feel that the drugs make up the prison they are subject to, that their lives are directly linked to schedules, schemes and doses demanded by the drugs. Daily management of treatment is difficult, not only because of the amount of drugs or their undesirable effects, but also because of the time that should be reserved for complying with the therapy. This *non-compliance* should be understood as not following all steps of the therapy, and as sub-doses at times and dates defined by the seropositive subjects themselves(10).

Representations about the disease and their way of coping highlight compliance to anti-retrovirals as a relevant factor, but also bring the reflections of the observed side effects as an obstacle that is difficult, although necessary, to overcome, as noted by the subject:

> Lady, I can't explain it, but I feel weird. I feel very sick, I feel weird, but I have to use it (Respect).

These difficulties highlight the decision of HIV carriers to change their lifestyles so as to manage and accept certain adverse effects. This situation was also evidenced in the following testimony:

> I took it for fifteen days, but I started to swell too much on the stomach. I have hepatitis C and that's why the drugs made me swell so much. I even had difficulty breathing, then the doctors said they'd change the drugs so that they wouldn't mess with my liver […] I felt no pain, no discomfort, only after my liver started swelling, then I felt really bad. I felt sick, the stomach swelled, difficulty breathing […] then I had to quit the drugs […] I see people feeling sick because of the meds, but I hope that doesn't happen to me. I'll have to wait and see (Self-Esteem).

In spite of advances in the elaboration of drugs, the side effects of anti-retrovirals are more and more frequent, and are generally the main responsible for discontinuing the therapy. The development of neuropathies, hepathotoxicity, pancreatitis, lipodystrophy, diabetes, dyslipidemia, osteoporosis and lactic acidemia are among the complications that can considerably worsen the HIV-infected individual's quality of life. It is important to note that there are countless drug interactions, some of which are responsible for the anti-retroviral therapy's loss of efficiency(5).

Diarrhea, gastrointestinal disorders (such as vomiting and nausea) and rashes are the most common side effects caused by anti-retrovirals. Lipodystrophy is a side effect caused by prolonged use of some anti-retrovirals, whose characteristic is the change in the distribution of fat through the body. Interference with the lipid metabolism and mitochondrial toxicity, associated to protease inhibitors and reverse transcriptase inhibitors, respectively, seem to be involved in the pathogenesis of lipodystrophy(5).

For lipodystrophy, the best preventive form is to practice physical exercise regularly, besides maintaining a healthy, low-fat diet. Some people even stop taking the medication in the hope of reducing the problem. However, it is known that the accumulation of fat in the abdomen and the nape, and the lack of fat in the legs, arms and face are rarely reverted with the interruption of the drugs alone(5).

Even for carriers who had no reactions related to anti-retroviral usage, concerns exist about what the person knows of the treatment and how this person shares the experience with patients who endure the side effects of the drugs in their daily routine:

> I saw it as another patient who was here, who felt sick and complained about it, but I hope that doesn't happen to me (Self-Esteem).

There are concerns about non-complying with the therapy in the statements of these subjects, but they do not always take action in terms of the need for compliance, even if they have the information that such interruptions can cause other difficulties in the reduction of vulnerability to the disease.

> Well […] I stopped, then I started again. Now I started it again. I stopped and restarted […] because I abused drugs, alcohol. Then I stopped the meds to do that […] I'd get hospitalized, sick. Then I took the meds in a hurry […] The doctor said that these relapses happened because I stopped the therapy many times (Solidarity).

> Sometimes I get suspicious and don't take it […] And that damages me, increases the virus again […] I think, but I stop and restart, you get it. But this time I stopped for a long time. More than a month. I'm worried, but my body is so tired of the drug that it can't take it anymore. I know I need it, but I can't (Hope).

The situation of constant treatment resuming, besides not producing the desired therapeutic effect, can contribute for the development of a viral resistance to the drugs used. This development of resistance and the subsequent loss of drug efficiency against the HIV are the primary barrier for the long-term efficiency of the treatment. The virus' ability of replicating itself has to be considered, thus generating spontaneous mutations of the viral genome(5).

Due to the complexity in handling medication, knowledge about these drugs is needed so that indications can be made at the appropriate moment: necessary changes, clarifications about side effects and, especially, making the user aware of the need to comply with the treatment, otherwise there will be no progress(5). The therapy, therefore, must not be started until the goals and need for complying with it are understood and accepted by the individual.

It is worth noting that, when HIV carriers start drug therapy, they may be confirming their status of infected persons to society, and that they need treatment in order to continue living. Such a fact can cause situations of prejudice:

> I told her, and she told everyone that I was sick and took medication (Hope).

This perception of HIV/AIDS carriers can lead them to really assume their seropositivity, or hide the drugs and the treatment from others, or even abandon the treatment:

> I have to take the meds, and I'm not gonna take them in front of my friends, right? They'll think I'm dying (Perseverance).

By trying to avoid situations that generate prejudice, HIV carriers carefully select the persons who can be informed, in certain circumstances, of their health condition. They understand that omitting the fact that they take the drugs avoids stigmatization, at the same time as they hide their disease.

The fear of discrimination causes users to hide their drugs or remove the labels of the bottles to avoid that people with whom they maintain professional or family relations suspect or discover about their disease(13).

Another aspect for non-complying with the treatment is the imminent perspective of death. Although they face the side effects, the routine, the prejudice and the lack of motivation, they also have the perspective that the treatment offered is not the cure, but merely a way to prolong survival:

> Because I don't want to fall ill again, and these drugs will prolong my life, so all I can do is accept them […] what can I do? I'll try. I want to get better, so I'll take the meds (Self-Esteem).

Facing all these physical and social situations, for some, is not worth it, since a definitive cure will not be achieved:

> You feel all that and still you can die. My partner treated herself the right way and died. These things take away your motivation, because you know that either now or later you will die too (Perseverance).

Seeing death as a burden ready to collapse over our destinies is unbearable. Living with the impression that it stalks us is very distressing(14). Therefore, thinking excessively about the disease is immediately related to sadness, producing effects in the body and considered an accelerant of the process of death(15). Therefore, professionals need to understand that the daily management of the disease by the sick individual is more frequently done according to social than medical criteria. This means that the control and treatment regimens are not automatically accepted, but are evaluated by the patients according to their consequences.

However, it is important to highlight the ambiguity that this imminent sensation of death can cause in other patients. Some, feeling like that, turn this feeling into a motivating point for complying with the treatment. Trust in the positive effects of the treatment makes the subjects believe that the treatment is their only way of living. This trust may be a consequence of the intense publication about the positive effects of the anti-retrovirals and the huge investments made in the field of specific drugs. Treatment with anti-retrovirals came as a great hope for those afflicted by the HIV virus. Although there are factors that make compliance difficult, there are some that motivate the carriers to comply with the drug therapy.

AIDS is represented by the patients as a constant struggle. These subjects see the need to leave the situation of contemplating what could not live before, so that they can start believing in the possibility of overcoming the disease(10). With all difficulties, they can see that the treatment with anti-retrovirals brings benefits when done correctly.

The main objective of anti-retroviral therapy is to delay the progression of the immunodeficiency and restore as much immunity as possible, increasing the time and quality of life of infected persons(5). The subjects believe, also, that this is the only way to keep on living and report that it is also important to associate the medication to changes in habits:

> I'll take more care of myself, avoid staying out in the cold, drinking, smoking. But taking the drugs is the main thing (Self-Esteem).

The perception of being seropositive seems to symbolize an opportunity to review life in relation to the other and to oneself. It is as if, in this often conflicting context, there were forces capable of changing the direction for taking a stand in the face of life, i.e. the possibility of leaving a state where there are no mobilizing forces for changes. The subjects reveal their mobilizing forces for taking a stand towards the disease and life(12). It is important to consider that nothing changes a man more than the awareness that his end is near(14).

Therefore, the HIV diagnosis pushes people to reflect about their behavioral patterns, beliefs and values. Reflection can trigger changes in individual behavior and, thus, minimize the vulnerability to disease(16).

Another point found for complying with the drug treatment was the will to live, the struggle for life:

> To lengthen it a little bit more, you know? If you don't take it, there are many complications. Then, as they say it, it serves to give you more strength, right?" (Friendship).

Although there are difficulties for complying with the treatment, the struggle is worth it for the subjects:

> They make me get better and make me be here. I need them, or else I'll die […] Look, lady, I'm young and I want to live. I can't work any more, I had no children, no wife, I live in a bed but I want to live. And the drugs make me live (Respect).

When the disease manifests itself, it can impose not only changes in the concrete organization of life, but equally set the course for the meaning of the individuals' existence, the image that they have of themselves and the explanations that they give.

An important point at the moment of compliance is the absence of imposition of the treatment by the professionals, since it should be accepted by the HIV carrier as something positive and that should not be faced only as medical prescription. The professional plays an important role in the mediation of the acceptance of treatment for the carrier, who seems to respond better to the proposal of compliance when well-oriented and monitored.

> He is […] excellent, very caring and attentive. Not to mention the attention that I receive at Hospital-Dia. They gave me a lot of support and care, they still help me out, and then I'm strong to go through with the treatment (Love).

For a better observance of the therapy, professionals need to perceive the meaning of seropositivity for the patient; be able to identify the moments of greater vulnerability for the patient; know the level of support and welcoming this patient can count on, and how the institution receives this patient(11). The conversation between the professional and the patient should not be unidirectional, as the pains of the latter affect and involve the former in solidarity, without imposing or judging, but clarifying, informing, talking, sharing comprehension and trust.

Good relations between the healthcare professional and the user are considered one of the main components for compliance. Therefore, at the moment of disclosing the diagnosis, it is important that the healthcare professional take into consideration the reactions and inform about the new possibilities of treatment and the resources currently available, which, if accessed, open other perspectives of life for infected people(17).

Therefore, the client's report seems to be, at this time, considerably more precise than the medical assessment. Asking specific questions, without judgment, can maximize the opportunity of obtaining useful information for treatment compliance. It is undeniable that this is a difficult process, because the most difficult aspect in medicine is arguably trying to decipher intentions contained in the statements of patients and their relatives(17).

Family support allows for better management of the situation, in case the disease is effectively installed. Besides, family members are usually the reason for undergoing treatment:

> After feeling angry, I started thinking about other people who like me […] the most important is my mother. And then I felt the will to live. The treatment is meant for the sick to

> live longer […] Nobody does the treatment if they don't want to live longer. Until now, I want it […] (Perseverance).

Concerns about the upbringing of children and the opportunity of seeing them grow up brings out an inner strength to keep on struggling for existence, as made evident in the statement:

> Now I have to treat it, because I have children and grandchildren who suffer when I get sick (Self-Esteem).

Seeing the importance of treatment, which could grant better chances of survival, does not guarantee its acceptance by the users, who seek other senses to associate it to the personal desire of living. The family, in the perspective of these users, is a mobilizing factor for compliance with anti-retroviral therapy. Therefore, they need to be considered by the care providers, who should identify them through the knowledge of the person receiving care, and try to insert them in this treatment process.

Patients who are capable of mobilizing both individual and social resources to cope with the situations tend to adapt better to their new condition. In this context, family and friends play an important role, as well as the professionals in charge of healthcare. Whatever the available resources at the healthcare services, they will not be adequately used if the patient is not welcomed by the professionals(18).

Religion is mentioned as an important motivating factor for compliance, since the search for spirituality provides support for people to carry on living and even change their ways of leading life:

> After we meet Jesus, our life changes (Solidarity).

Religious beliefs are important, but the possibility that the carriers feel so protected by religion that they decide to abandon the treatment cannot be overlooked, or believe that treatment is unnecessary and that they will be blessed with a cure. Nursing healthcare should assure respect to one's beliefs and faith, exercised through strengthening and valuation of practices related to the spiritual life of those people.

HIV carriers in treatment end up developing coping strategies for the disease and the suffering they are subject to. Thus, it is important to count not only on the support of professionals and relatives, but also of the whole society.

FINAL CONSIDERATIONS

This study made it possible to notice that AIDS is a disease that brings several feelings to the life of patients, such as fear, prejudice and uncertainties. The research also noted, strikingly, that prevention is still thought of as the responsibility of the other.

In this context, drug treatment emerges as a hope of prolonging existence. At first, patients have a lot of hope, as if it were something that could solve their problems. With the utilization of specific drugs, they start to feel that, behind the benefits, there are also setbacks that are difficult to overcome. They need to find ways of coping so that they can still go on in their quest for life. Therefore, since complying with the treatment is something of great significance for the study subjects, where factors like side effects, hampered social life, financial difficulties and prejudices are difficult to overcome, it is fundamental that, to obtain this compliance, they seek other motivations, such as family, children, will to live, fear of dying and religion.

Accepting that treatment compliance by HIV/AIDS carriers includes everyone's actions and, consequently, that non-action too is everyone's responsibility, is not acceptable, since that would be only blaming the individual instead of getting to know and understanding his difficulties. Therefore, treatment compliance involves a relationship between the patients, the healthcare service and the professionals, where they should be placed as the subjects of this action, since treatment is often performed at home.

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