ADULTS IN ANTIRETROVIRAL THERAPY FOR THE HIV/AIDS: IMPLICATIONS IN THE DAILY LIFE

ABSTRACT

Objective: To describe the implications associated with the daily life of adult carriers of HIV/AIDS with sights to follow-up on the antiretroviral therapy. Method: It is a qualitative study that was developed in 2011, in a hospital from the Mid-West Region at the Rio Grande do Sul State/RS/Brazil. For the data production, we have performed the Dynamics of Creativity and Sensibility (DCS), Talking Map, with a group of four participants. We have applied the technique of analysis thematic of the content. This research project was approved by the Ethics Research Committee, CAEE n° 0090.0.243.000-07. Results: From artistic productions and testimonies, two categories have emerged: << Facing the everyday of having HIV/AIDS >> and << The implications of the therapeutic daily routine and of the social networks of individuals with HIV/AIDS >>. Conclusion: Before the implications related to the daily lives of adults with HIV/AIDS, it becomes necessary having permanent health monitoring, including individual and group-related actions with sights to promote and support the implementation of the antiretroviral treatment. Descriptors: Adult’s Health; HIV; Acquired Immune Deficiency Syndrome; Highly Active Antiretroviral Therapy; Nursing.

RESUMEN


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Objetivo: describir las implicaciones relacionadas al cotidiano de adultos con el HVI/SIDA para dar seguimiento a la terapia anti retrovirual. Método: estudio cualitativo, desarrollada en 2011, en hospital de la Región Centro-oeste de Rio Grande do Sul/RS/Brazil. Para la producción de los datos fue realizada la dinámica de creatividad y sensibilidad Mapa Hablante, con un grupo de cuatro participantes. Fue aplicada la Técnica de Análisis temática del contenido. Esta investigación tuvo el proyecto aprobado por el Comité de Ética en Investigación, CAEE n°: 0090.0.243.000-07. Resultados: de las producciones artísticas y declaraciones surgieron dos categorías: << Enfrentando el cotidiano de tener el HVI/SIDA >> y << Las implicaciones del cotidiano terapéutico y de las redes sociales de los individuos con el HVI/SIDA >>. Conclusión: delante de las implicaciones relacionadas al cotidiano de los adultos con HVI/SIDA es necesario que el acompañamiento permanente de salud deba contemplar acciones individuales y grupales para promover y apoyar la realización del tratamiento anti retrovirual. Descriptores: Salud del Adulto; HIV; Síndrome de la Inmunodeficiencia Adquirida; Terapia Anti Retrovirial de Alta Actividad; Enfermería.
INTRODUCTION

The prevalence of cases of Acquired Immunodeficiency Syndrome (AIDS) in Brazil, between 1980 and 2011, is concentrated in the age group from 25 to 49 years old, constituting the adult population. With the introduction of the antiretroviral therapy (ART), from 1996, there was a significant reduction in morbidity and mortality associated with the disease at stake. Nevertheless, the success of the ART therapy is influenced by the treatment adherence, given that it is considered the major determinant of therapeutic response and, furthermore, the greatest challenge for its maintenance.

Increased life expectancy and disease chronicity bring up demands on the public policies and health care services. In addition to implications of the therapeutic daily routine, which is permeated by factors related to continuous needs of monitoring the health of people with HIV/AIDS, given that they require frequent visitations to health care services, assessment of adherence levels, coping strategies towards the side effects due to medication, adaptation of routine and influence of the social support.

Thus, adherence is a dynamic and multifactorial process that includes physical, psychological, social, cultural and behavioral aspects, which requires shared and co-responsibilized decisions between the people with HIV/AIDS and the health staff, together with the social network.

Thus, we have elected the need to know the routine of people with HIV/AIDS as the focus of this study, with sights to keep on the therapy, since it involves a process of adaptation, which require changes and adjustments in the patient’s lifestyle. Accordingly, this study aimed at describing the implications related to daily life of adults with HIV/AIDS, in order to follow up on the antiretroviral therapy.

METHOD

It is a qualitative study that was developed in the second half of 2011, in the infectology service from the University Hospital of Santa Maria (known as HUSM), located in the Mid-West Region at the Rio Grande do Sul State/RS/Brazil.

The study subjects met the inclusion criteria, namely: aged between 20 and 49 years, to be in ART therapy and registered in the Medications Dispensing Unit (UDM) from the HUSM. To form the group, the patients were invited to participate in the study during the nursing consultations in the Outpatient Clinic for Infectious Diseases of the aforementioned service. Thus, we have scheduled day, time and room for the development of the dynamics.

On the dynamics day, the guests who agreed to participate in the research signed the Free and Informed Consent Form, being that a group of four participants was gathered for the dynamics, three were female and one was male.

For the data production, we have used the Dynamics of Creativity and Sensibility (DCS), based on Creative and Sensitive Method (CSM). This method is subsidized by the critical-reflexive pedagogy of Freire and provides an alternative to nursing researches, considering its study object and its peculiarities, enabling a better understanding whether they are investigated and discussed in group. DCS offers a space for collective discussion, in which the experience is addressed by means of an artistic production.

In this research, we have developed the Talking Map Dynamics, which is characterized as an artistic production, since it is the construction of a map drawn by the participants with sights to describe the implications of ART therapy on the daily lives of adult carriers of HIV/AIDS.

The development of DCS took place through five stages: 1 - consisted of the presentation of the researcher and the dynamics’ auxiliaries as well as the presentation of the participants to the group; 2 - presentation of the objective of the dynamics and the way in which this would be developed; 3 - presentation of the guiding question: from your home, what are the places where you go to follow-up the treatment for the HIV/AIDS? And provision of guidance to the participants to conduct the artistic production; 4 - presentation and discussion of artistic productions of the participants; 5 - Accomplishment of the synthesis and validation of results by the group.

We have performed the transcription of dialogues and, for conducting the data analysis, we have used the technique of analysis thematic of the content, which consists in finding meaning units, whose presence or frequency are expressive for the pursued analytical objective. It has been consisted of three stages: sorting, data classification and final analysis.

The sorting phase consisted in transcribing the recorded data and in the thorough reading
of the research corpus, in order to determine the recording units: phrases or keywords that appear with a certain frequency in the statements, which are characterized as central ideas or relevant aspects; followed by the determination of the contextual units: delineation of the context of comprehension of the recording unit.

From that determination, we have conducted the thorough reading of the research corpus and the exploration of the material through the clippings of text fragments of the recording units. The classification phase has allowed us to build the empirical categories responsible for the specification of the themes and theoretical concepts that guided the discovery and construction of the meaning units, which give the foundation of the analysis. For this purpose, we have developed an analytical framework that enabled the emergence of two categories: Facing the everyday of having HIV/AIDS; and The implications of the therapeutic daily routine and of the social networks of individuals with HIV/AIDS.

The phase of final analysis was based on the treatment of the results and interpretation thereof, seeking to articulate the structured material with the ideas of interviews and theoretical foundation, thus aiming at identifying the underlying content of what is manifested.

This study followed all ethical precepts in accordance with the Resolution n° 196/96, being that it was approved by the Ethics Research Committee from the Federal University of Santa Maria, under the CAEE number: 0090.0.243.000.

RESULTS AND DISCUSSION

The constitution of the category “Facing the everyday of having HIV/AIDS” started from the identification of words and expressions that were more frequent in the testimonies of adults participating in the dynamics. The recording units that have configured this category were: impact of the discovery of the diagnosis; fear of revealing the HIV/AIDS due to the people’s reaction; normal life in spite of the disease.

According to the respondents of this study, the discovery of the diagnosis was difficult, because they have never imagined that this could happen to them, thus they did not feel vulnerable to the condition of acquiring HIV/AIDS, as can be seen in the following speeches:

[...] So, at first it was difficult, it was a labor for both [couple], neither of the two was expecting [...] we never thought it would happen to us [...] (A3)
[...] We never think it can happen to us [...] we always expect that it happens with the other people, but not with us. (A2)

The influence of the impact in the discovery of the diagnosis presents a different self-perception of vulnerability in relation to the HIV virus among men and women. The female vulnerability has been flagged by the subordination of women to the male desire, being determined by conflicting relationships with their own sexuality. The female identity is constructed from cultural and social determinants that reinforce the love as a kind of protection, thereby establishing risks in light of the sexually transmitted diseases, such as, for example, AIDS.8

From this perspective, women do not realize themselves vulnerable to the HIV virus, having an unexpected impact in the discovery of the diagnosis, since the vast majority of these ladies was infected by their own sexual partners. The confidence in its own sexual behavior, monogamous, is a justification presented by women to their low self-perception of vulnerability and, therefore, as a reason for that the use of condoms is relativized.9

Before the discovery of the diagnosis, there is the fear of disclosure of their diagnosis to other people, due to the reaction that they could demonstrate, as can be seen in the following stretches:

At first, he said nothing to the family, I was afraid that someone came home and saw that situation [...] So, when I told, they [family members] already thought, well, I was with one foot in the grave, then it was pretty shocking to them. (A3)
So, I met my husband in this situation. He is HIV-positive patient, because I’ve met him as a seropositive subject. He even told me, I was afraid to tell him that I was too. (A4)

The discovery of the diagnosis results in fear of unveiling that clinical condition to other people, which is directly related to the expectation of others’ reactions. The discovery of the disease is a time of transition in the life of the person, which ends up disrupting its daily life. Accordingly, the suffering becomes present when this subject is faced with an irreversible reality. Although AIDS is now considered as a chronic disease, ends up generating negative feelings, such as: anxiety, sadness, fear of disease, death and rejection.10

The stigmatized nature of the AIDS epidemic hinders the disclosure of the diagnosis of individuals with HIV/AIDS in direction to other people, due to the fear of
with HIV/AIDS can keep themselves healthy for many years. Staying healthy refers to having a normal life, with adaptation and acceptance of the seropositivity and the accomplishment of the ART therapy. 

It should be perceived that this process of naturalization is linked to successful treatment. Nonetheless, this depends, above all, on discipline and requires some care procedures, which encourages them to incorporate healthy life habits into the daily routine.

Such naturalization is associated to the necessary care to live well, such as regular intake of medication, as well as attendance to consultations and examinations, which triggers the reduction of the vulnerability to illness.

The constitution of the category “The implications of the therapeutic daily routine and of the social networks of individuals with HIV/AIDS” was held by means of the recording units: coping with side effects of medications and social support networks.

The interviewees perceive the importance of properly performing the treatment, making the continuous monitoring in the hospital environment, keeping the routine of medications even with side effects and changing the behavior of misuse alcohol and drugs:

 [...] I establish goals and one of my goals is the continuous treatment [...] every medication, even the ASÁ, provokes a side effect, then the antiretroviral is a medication much more complex. [...] The worst of all are the side effects. [...] As to the treatment adherence, many people don't do because of the side effects, because they are not accustomed to that routine [...] I have nausea in the morning, I make the treatment with Efavirenz [remedy brand's name] since 2003 [...] even today I live with side effects aroused from it. (A1)

 [...] We die with AIDS and not die due to AIDS, you have just to make everything right [the treatment] [...] when I was not feeling well, I didn’t take the medication; when I went realizing it, there was already eight months with no medication [...] then it has been engaged the reverse gear [...] (A3).

I came here [hospital] drugged, the infectologist served me, gave me some medications, I put out, but today it is another life. [...] Today, I take my medications, I don't use drugs, I don't drink; I do my treatments rightly [...] That's bad to take those remedies. [...] They burn my stomach. [...] There is one that makes me crazy. (A4)

 [...] I was with 6 months and a little more of pregnancy, so we started to take the...
Life with HIV/AIDS goes through the continuous use of antiretroviral drugs, as well as the adjustments conducted in the daily life for administering these drugs. Thus, people affected with the disease need to deal with such adversities in the pursuit of a healthier life. The treatment process is often painful, full of difficulties to be overcome, such as the adaptation of the routine in relation to the therapy and its daily routine.

The presence of side effects is a factor highlighted by the speeches and ends up affecting the gastrointestinal tract, given the potentiality of these medications. Each user’s difficulty in performing the treatment should be approached with care and attention by a health care professional, so that it is always an ally in its adherence to the antiretroviral treatment.

Moreover, the medicating regimen might compromise the therapeutic process because of its complexity. This factor is associated to the amount of medications, the adverse reactions, the use of psychoactive substances, the incompatibility between the use of medications and the use of drugs, the difficulty in understanding the benefits of the treatment and implications of the inappropriate usage.

The subjects, through testimonies, reported that they did not give continuity to the treatment in the asymptomatic phase of the disease, also due to the misuse of alcohol and other drugs, thus compromising the treatment. The risk of treatment interruption is considered a critical problem, especially for those who are starting the treatment. This problem increases the possibility of not performing the treatment for those who make use of licit or illicit drugs, and those using psychiatric medication.

Regarding the measures that help in achieving a proper treatment, one can make use of strategies such as formation of more effective adherence groups, which converges with the statement of the subjects that the group approach might be beneficial, answering the expectations and doubts arising from the ART therapy:

- I wish these meetings could happen more often so, I hope that this experience continues working.
- If I enter into a group, I’ll see that there are people in the same situation as mine, so I will not need to be opened to people who could suddenly criticize me.

In the context of therapeutic daily routine, the support from the family, the partner and the friends, who make up the social network of this population, is essential to overcoming the disease, to cope with the demands arising from the treatment and for better coexistence with the disease:

- My biggest support comes from inside my household, my mother, she is the pillar in my treatment, which directly reflects in my survival. It’s good to share with people the pain that you feel; you should not guard it only for you, because the pressure is too great.
- Facing the disease would be a very complicated thing, I would not have to reckon on, I cannot reckon on the mother-in-law. My husband knows, my sister knows, those times I told my son and I think that these people have to know about that, no one else.

It is understood by social network the group of people, organizations or social institutions that maintain connection through some kind of relationship. In this sense, the concepts of social network and social support have been configured as resources applicable in the nursing practice, with a more comprehensive gaze on the social context, providing the improvement of the quality of life for people carriers of HIV/AIDS.

It is understood that the support is essential for facing and overcoming the disease, above all, in the accession process. It should be evidenced that people with HIV/AIDS who have strong social networks, have better operating conditions of the cognitive, affective spheres, as well as in relation to social relationships. In addition, they show greater satisfaction with such aspects.

For this purpose, it is necessary that...
actions of care and health education, individual and group-related, seek to understand the people’s trajectory with sights to perform the treatment and to have as aim the strengthening of support networks. Therefore, it is essential to develop actions of shared care among the health care staff, family members/caregivers and adults with HIV/AIDS.

CONCLUSION

The discovery of the diagnosis is configured as a pretty impacting issue, since the subjects do not see themselves as components of a vulnerable group to the HIV virus. When they discovered that they are infected, it raises the question of fear of people’s reactions because of discrimination, prejudice and stigmatizing nature of the disease, restricting the support network. For people with HIV/AIDS, the act of unveiling their diagnosis is a very painful time, followed by feelings of anxiety and fear.

With the adaptation to the serological condition, it raises the implications in the daily life, such as the need to have a normal life in spite of the disease and the naturalization attached to the success of the ART therapy. Such a treatment is directly related to adherence, which depends on discipline, confrontation of side effects, behavioral and dietetics changes, compliance with the prescribed dosages and schedules. These measures might be added to the clinical and laboratory monitoring.

The support from family, partner and friends is essential in the everyday life, since solid social networks exert a protective role, influencing in the quality of life and well-being of the individual.

It was concluded that the continuous monitoring of health should cover individual and group-related actions with sights to promote and support the implementation of the antiretroviral treatment, considering the individual behavior and its social network. Furthermore, the health care service should conduct health education activities, seeking to welcome, admonish and monitor the people carriers of HIV/AIDS and their families.

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