



HIV/AIDS Treatment Regimens Adherence in Women*

Experiência da adesão ao tratamento entre mulheres com Vírus da Imunodeficiência Humana/ Síndrome da Imunodeficiência Adquirida

Experiencia de la adhesión al tratamiento de mujeres con VIH/SIDA

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ABSTRACT

Objective: To understand HIV/AIDS treatment regimens adherence experience in women. **Methods:** An ethnographic study, based on the interpretative anthropology framework, was conducted with women who were participating in an “Adherence Group” at a public hospital. Data were collected through semi-structured interviews and participant observations from January to December 2007. **Results:** Four categories emerged: (1) confronting the values regarding the experience in participating in treatment regimens adherence, (2) the singular experience to the treatment regimens adherence, (3) customs and practices regarding the experience in participating in the treatment regimens adherence, and (4) caring in the interpersonal relationships. **Conclusion:** The HIV/AIDS regimens adherence experience was unique to each participant; however, women speeches suggest directions for effective HIV/AIDS treatment regimens adherence. Each women unique experience may show others ways to come out of the shadows of a stigmatizing diagnosis.

Keywords: HIV infections; Acquired immunodeficiency syndrome; Antiretroviral therapy, highly active; Nursing care; Patient Acceptance of health care

RESUMO

Objetivo: Compreender a experiência da adesão ao tratamento para o Vírus da Imunodeficiência Humana/ Síndrome da Imunodeficiência Adquirida para a mulher. **Métodos:** Estudo etnográfico, baseado no pensamento teórico interpretativista, com oito mulheres de um Grupo de Adesão em um hospital público. Os dados foram obtidos por meio de entrevistas semi-estruturadas e observação participante de janeiro a dezembro 2007. **Resultados:** Emergiram quatro categorias: enfrentamentos aos valores da experiência da adesão ao tratamento, a experiência singular na adesão ao tratamento, costumes e práticas na experiência da adesão, o cuidar nas relações interpessoais. **Conclusão:** As experiências relatadas pertencem à vida singular de cada informante; no entanto, o caminho para uma adesão efetiva fica translúcido nas narrativas. Partiram da realidade específica de suas vidas para ensinar o caminho para aqueles que desejam sair da sombras de um diagnóstico estigmatizante.

Descritores: Infecções por HIV; Síndrome de Imunodeficiência Adquirida; Terapia anti-retroviral de alta atividade; Cuidados de enfermagem; Aceitação pelo paciente de cuidados de saúde

RESUMEN

Objetivo: Comprender la experiencia de la adhesión al tratamiento para el Virus de la Inmunodeficiencia Humana/ Síndrome de la Inmunodeficiencia Adquirida de mujeres. **Métodos:** Se trata de un estudio etnográfico, basado en el pensamiento teórico interpretativo, realizado con ocho mujeres de un Grupo de Adhesión en un hospital público. Los datos fueron obtenidos por medio de entrevistas semi-estructuradas y observación participante en el período comprendido entre enero a diciembre del 2007. **Resultados:** Emergieron cuatro categorías: enfrentando los valores de la experiencia de la adhesión al tratamiento, la experiencia singular en la adhesión al tratamiento, costumbres y prácticas en la experiencia de la adhesión y el cuidar en las relaciones interpersonales. **Conclusión:** Las experiencias relatadas pertenecen a la vida singular de cada informante; no obstante, el camino para una adhesión efectiva se refleja en las narrativas. Partieron de la realidad específica de sus vidas a fin de enseñar el camino a aquellos que desean salir de las sombras de un diagnóstico estigmatizante.

Descriptor: Infecciones por VIH; Síndrome de inmunodeficiencia adquirida; Terapia antirretroviral altamente activa; Atención de enfermería; Aceptación de la atención de salud

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INTRODUCTION

In the past few decades, there were important advances to the Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome (HIV/AIDS) treatment through the combined antiretroviral therapy⁽¹⁾. However, the medication guarantees the treatment effectiveness, for “increasing patients` adherence to the treatment is a core concern to prevent the epidemic from evolving”⁽¹⁾.

The high-activity antiretroviral therapy brought more quality of life to people who live with HIV/AIDS. Nevertheless, researches show another picture, the body marks, and the image that has to be taken care of, when the side effects produced by the inhibitors come up, such as: lipodystrophy, cardiovascular disease risks, dislipidemy, hyperglycemia, factors that have to be considered when living with HIV/AIDS⁽²⁻⁴⁾.

Although there are data demonstrating improvements to HIV/AIDS infected people survival in the past ten years, mainly due to the preventive methods to the medical therapy, the adherence is still a great challenge and a strategic process to healthcare and public policies that take care of the Sistema Único de Saúde (Public Healthcare System) clients in Brazil⁽⁵⁻⁶⁾.

In spite of all the difficulties inherent to the healthcare services, gender issues, and consequently, the social and cultural processes vulnerability, there is a relevant number of women that experience the treatment properly⁽⁷⁾. This article study object is an attempt to understand another face of the treatment phenomenon, that is, the experience of the women who adhered to the treatment. We believe that, once these factors are better understood, ways can be pointed out so as to perform a more effective nursing care to those who have difficulties having a regular follow up.

Upon such aspects, the general objective was to understand the HIV/AIDS treatment adherence as of the women`s experience; and the specific objectives were to describe how the HIV/AIDS treatment adherence interferes and integrates to the women`s daily process, identify what women do to maintain themselves in the HIV/AIDS treatment, and identify the control mechanisms that generate the HIV/AIDS woman experience, demonstrating adherence to the treatment.

METHODS

The Anthropology interpretive theoretical thought was chosen to be the guideline in this study. To do so, Geertz⁽⁸⁾ assumptions were used as a theoretical basis to conceptualize culture. Culture is comprised of a symbolic system, built by people in a social group, and it guides their way of thinking and acting in society. The author

states that his analysis is essentially semiotic, that is, interpretive and inductive. The explanation for such phenomena, as of an inductive analysis requires letting go of the giant cause and effect webs. Therefore, the culture interpretive study produces an effort to believe and accept that each human being has a way of living and building their lives⁽⁹⁾.

The research obeyed to the guidelines provided by Resolution n.º 196/96 from the Conselho Nacional de Saúde (National Health Council), and was approved by the Comitê de Ética em Pesquisa do Hospital das Clínicas de Goiás (Research Ethics Committee of Goiás Hospital). (Protocol n.º 155/06). The study field was the Adhesion Group (AG) of a public hospital in Goiás, a reference hospital for the transmissible disease healthcare, located in the city of Goiânia.

Eight women took part in the study; their ages ranged from 31 to 58 years, and they were part and/or participated in the actions and projects developed by the AG. They also presented a positive diagnosis for HIV/AIDS for at least 2 years. From these women, three were indicated by AG professionals and five were chosen through the observation technique. We reinforce that the number of informants in the study was enough to guarantee the information recurrence⁽¹⁰⁾, and through it, built a diversified information set that would allow similar and different significations regarding the antiretroviral treatment to be captured.

The field work occurred between January and December, 2007, when the semi-structured interview and participating observation techniques were utilized, and notes taken on a field journal. The interview script was comprised of core questions: How did you find out you had AIDS? Tell me about your experience adhering to the HIV / AIDS treatment. What changes to your life occurred after the treatment? How have you been dealing with the financial barriers? Tell me about how you face the stigma. Would you like to say something I did not ask? Through these questions, we attempted to explore the aspects concerning the HIV / AIDS treatment experience since the discovery of a positive HIV result up until the interview moment, which was performed with pre-defined location, date, and hour.

When the data collection period was finished, and all the material originated from the interviews had been transcribed and organized, along with the field journal notes, the coding process was initiated. Initially, exhausting readings of the transcriptions were done so as to identify the core ideas that were grouped in signification units, according to their similarities, from which emerged the thematic categories, guided by the content analysis assumptions⁽¹¹⁾. Therefore, data indicated the existence of four categories, that is, different ways of facing the experience of adhering to the

treatment, the singular treatment adherence experience, habits and practices acquired when adhering to the treatment, and the care concerning the interpersonal relationships. And finalizing the analysis movement, we aimed to theorize the material and the respective analytical reflections with regards to what was interpreted⁽⁸⁻⁹⁾.

RESULTS

Among the eight informants, four worked as craftsmen; one was a housekeeper; one was a cook, and two were housewives. Four of them did not conclude the elementary school, and others had returned to school, after the diagnosis was confirmed. One of the informants had been diagnosed with HIV/AIDS infection in 1989, and she was the oldest in the group; the most recent one had been diagnosed in 2004. Informed I-1 narrated she had used injecting drugs, thus she did not know which was the contamination way; the other women narrated they got infected by the HIV sexually, with their fixed partners. Seven informants conceived children after the diagnosis. Below, we describe the elaborated signification units.

Facing the experience values after adhering to the treatment

Through this signification unit, women narrated that facing the adherence experience consists of searching for accepting the diagnosis, the changes that occur to the body, how important it is to maintain the diagnosis secrecy when interacting with other people, and the strong stigma people who live with HIV / AIDS have to face:

I was very confident, even my sister said: why doing the HIV exam? You don't have it! If you had it, you would have died by now, you were sick four times before! And then I thought: I'm already in trouble, what else have I got left? I have to do it. I got drunk and did it. When heard the diagnosis...my head got a bit disturbed, because I kept thinking that wasn't happening to me. (I-6)

(...) when the AZT got ready I didn't take it! I was afraid. We get transformed, like people from Ethiopia. My weight went down to 23 kilos, my skin got darker. My hair...it looked like a child's hair! People were curious to see someone with AIDS. Most of people would die...because there was only one type of drug. Later on, when they invented other drugs, I started to see that people remained alive longer, and then I thought: I'll try and take it... (I-1)

They (her children) don't know I have AIDS. I thought: No way can my daughter know about this! Let us see what they think of it later on. So far, I don't have the courage to say it, I'll wait for them to grow up a bit...they are innocent after all. What if they get to school and say, "My mom has AIDS". (I-5)

The treatment adherence singular experience

The informants' description about the treatment meaning in their daily lives and how they were able to keep doing it revealed diagnosis acceptance feelings, learning with the past in order to re-signify the present, and afterwards, the regular ritual of taking the medication, flowing towards the core goal, which is the wish to stay alive:

I am aware that if I don't take the medication even for one day, the "worms" – I'm going to call them "worms" – grow, and other "worms" join them, and after a day, they'll be more than a million. (I-1)

It means everything in my life, if I don't do the treatment, I might go sooner than I would want...so, it is very important for me...I love my life and I want to live, this is what makes me follow the treatment properly...I'll die one day, I know this day will come eventually, but I'll fight so that it doesn't come anytime soon (smiles). I think my life is so good, that is why I never forget to take my medication. (I-1)

Habits and practices when adhering to the treatment

The habits and practices are cultural, and the aspects that emerged from the women's experience narration were related to work, eating habits, sexuality and religion.

My work is my life; I work in order to pay my bills! I don't make much money, sometimes I sell a lot, sometimes I don't, and I have to make money for my boy. I didn't receive anything from the government. Thus, the food basket they give me helps me a lot at home, because if I have any money left, which is rare, I buy food and fruit, if not, I don't buy anything extra... (I-1)

I made a deal with God: If I managed to remain two years with the same medication, until the new medication came up, I promised I wouldn't do any extravagance. I'm sure God heard me, because in the past I wasn't able to keep the same medication for more than 6 months, and I needed to keep it for 2 years...It's been 4 years now (with the current scheme). So, I'm absolutely sure that God helped me. It was Him; he has a plan for my life. (I-7)

Of course I like bugs; I feel like doing it, but I'm controlled. But when it gets to the condom part, old men usually don't want to use it, they say it is like chewing gum with the paper, and with the young ones, I don't have enough courage to do it. (I-8)

Care concerning interpersonal relationships

In the informants' narrations, the interpersonal relationships care with regard to family was evident for HIV / AIDS women, however, the healthcare professionals had an essential role in the treatment adherence process, helping women living with HIV / AIDS overcome conflicts both in the material and emotional aspects:

Their love spoke loud to me; they do not have prejudices or discriminate people. On the contrary, they accepted me, gave me much love and care... (I-6)

In order to remain in treatment, the informants said they found strength in motherhood.

Well, the treatment helps us not to stay sick. If I get sick, I'll have to stay in the hospital, and staying in the hospital is not good for me. The boys only depend on me... In the past, I did not think like that. Nowadays I have to take care of myself and my children, because if I am well, they'll also be well... (I-5)

Nothing prevents me from being treated! Nothing! Nothing! It is because of my treatment that I am still alive! I am still working, studying, running after my objectives. I intend to reach them and see my daughter grow up. This is my dream, and I'll see it come true, for sure! Look at me... it is the medication, do you understand, the medication... and the will to see my daughter grow up... (I-6)

DISCUSSION

This group was comprised of young women belonging to an economically active age range, who see in their work a useful way of living their lives and an important income source to guarantee their living and their families'. Just as the return to the studies may indicate improvement perspectives in life conditions and a better future, religion also has a remarkable role on six women's lives, for believing in the sacred makes them find strength in order to continue fighting to maintain their lives.

When a person is diagnosed, they can choose a routine for the therapeutic process. However, the process is not always the result of a consensus between the healthcare professional and the woman, but a negotiation concerning the disease signs and its interpretations⁽¹²⁾. Being diagnosed with HIV/AIDS does not consist of pacifically accepting the disease; such process is built upon facing intrinsic cultural values as of what the woman and the world around her think of the disease. The narrations allowed us to understand that, when being diagnosed with HIV, these women would think it could be anything, but AIDS in their imaginary, as the above mentioned I-6 informant's speech reveals.

Just as facing a diagnosis is not so simple, accepting the changes to the body due to a treatment is one of the greatest confrontations the informants highlighted through their speeches. I-1 has been going through the antiretroviral treatment since the first pills released in the market to treat AIDS came up. Becoming confident enough to adhere to the treatment only happened when she saw the effects brought to other AIDS infected people's lives. The same participant experienced the visible body marks the disease generates, which are, in

people's imaginary, associated to proximity of death. This is what happens with AIDS: the body clearly shows the low immunity conditions. The mortal body produces feelings, speeches, and practices that sustain social life; the body feels, dialogues, shares meanings; the body is life, that is, "the body is culture" and the images about it are not fixed, they can be changed by the emotional state, disease or incapacity, or by the treatment itself⁽¹²⁻¹³⁾.

In the narrations, it is possible to observe that living with an HIV/AIDS diagnosis is like facing a secret that evolves to a cycle of actions, taking the women towards a "ritual" of covering it. Such cover is maintained in the social relationship cycles with children, family, school, leisure, and neighbors. Informant I-5 mentioned her kids do not know of her diagnosis, although her older son reminds her of medication hours; she says she would not be able to cope with people mistreating her children because of her diagnosis. She believes her children are not mature enough to face the prejudice, as it was revealed by her speech.

Not revealing an HIV/AIDS diagnosis can be understood as a need, because AIDS is a popular disease, characterized by a disturb in social and moral order⁽¹²⁾. Telling the secret to someone may alter one's identity; therefore it is better if the other person, whoever they are, does not know about it⁽¹³⁾.

The prejudices and stereotypes related to AIDS lead society to a stigmatization of people who live with it. AIDS becomes, then, a "social deviation", because besides the factors associated to the disease, it goes through a process that is full of symbolisms and interferes in the women's interpersonal relationships⁽¹⁴⁾.

The informants' acceptance of the treatment was only possible when they recognized it was the way to a better quality of life. The disease impact was experienced with insecurity, fear, discrimination, and loneliness.

The informants narrated that the treatment adherence starts when they recognize how necessary it is. None of them effectively adhere to the treatment until they acknowledged they had HIV which had already developed into AIDS. Such consideration is illustrated by I-1, who said to her partner she wanted to change her life in order to follow the HIV/AIDS treatment; her partner did not want to do it and passed away.

Each cultural group recognizes "being sick" in a different way within their social relationships and natural environments, attributing to the experience their respective significations. Therefore, the laboratory diagnosis does not mean the woman is going to accept her condition of having HIV or even having AIDS⁽¹²⁾. Such process does not occur in a certain amount of time, but will impact each woman's consciousness in a different way. When thinking about the past, what choices she made that may have led to the disease, the woman

with HIV/AIDS rises up and re-signifies her present and future, with quality of life. The recognition of how important life is gives strength to I-8 to continue the treatment. The desire to live is so big, she overcame the barriers to adhering to the treatment.

As of the moment the woman accepts her diagnosis, the conditions for her to deal with the medical therapy are set. There is a negotiation upon the therapy acceptance, which has to consider the disease signs among the process participants⁽¹²⁾.

In the informants' speech, regularly taking the medications becomes a daily ritual. Time paces their choice for life, according to I-1 narration.

When the informants go through the therapeutical assessment for the picture, they know the medication will have to be taken "for life", thus, they will have to learn how to deal with it day-by-day. In AIDS case, a disease that threatens life and challenges the meaning of human existence⁽¹²⁾, the woman tries to find strength in her objectives, goals, and future life perspectives in order to adhere to the therapy.

The cultural habits and practices when adhering are related to work, eating habits, sexuality, and religion for these women.

The informal work was considered a process through which they felt useful and dignified of having an identity, keeping interpersonal relationships active along the journey of living with HIV/AIDS, aiming not to be victims anymore, but fighters for life, according to I-1.

The remunerated work and the social and economic conditions were considered essential to maintain the treatment adhesion by HIV/AIDS infected women. The social and economic dimensions interfere on how they will live with HIV/AIDS, for the medication demands good eating habits, going to the routine appointments requires time, as well as financial resources for transportation tickets and extra medication (vitamins, anti-inflammatory, among others), besides, of course, maintaining their homes⁽¹⁵⁻¹⁷⁾.

Good eating habits became an important aspect in informants' lives as part of the treatment; however, the pauperization is still a barrier for the quality and quantity of food to be ingested. In western society, food is not only a nutrition source, but it is also connected to social, religious, and economical aspects. Food is inserted into cultural habits and practices people are used to living, where a universe of symbolic meanings can be found⁽¹⁴⁾.

Just as food, the medication use becomes a routine in the women's daily lives. I-6 says the side effects are hard to take, but persistency conducted to the medication, and she got better and adapted to it.

The correct medication usage has been taking HIV/AIDS infected women to bring their lives closer to the

normality, re-conquering what was lost with the diagnosis, rescuing their personal identities^(14,18). Once the treatment is happening, people assess its results. Nevertheless, they are aware the disease will remain, and that is the reason why the treatment monitoring and the constant assessments are done to their lives⁽¹²⁾.

They know that, if they do not take the medication, a series of opportunist diseases may occur and threaten their lives, as well as challenge their life experience meaning. The medication usage will not eliminate the AIDS stigmatization, but gives the women an "almost normal" standard proximity, so that they can live in society.

For the woman with this diagnosis, the use of condoms must be part of the treatment; however, it normally generates conflicts between the woman and her partner, as it was highlighted by I-8 speech.

In certain societies, the condom use can be a threat to reproductive health, as well as men see it as an inhibitor of the pleasure capacity generated by the sexual act. Some anthropologists stated that such ideas could be connected to the masculine identity, which could undermine the relationship between the two parts⁽¹³⁾. We need to understand sexual interactions are linked to a context, where individual negotiations between the parts involved occur concerning sexuality and condom usage.

A practice that became a reality to these women's lives after the HIV diagnosis was religion being part of it. Sealing a deal with God so that the organism accepted the medication was essential for I-7. Once her body did not accept the cocktail, the way she found to try and adapt to it was sealing a pact with God. Faith in God, along the treatment trajectory, is a reason to live. Religion helps people cope with the emotional pressures; it is a way out and an empiric explanation for chaos, and misfortune. Religion helps the women face questions they do not have an answer for; it helps them find strength to overcome the affected moral limits⁽⁵⁾. Therefore, through religion, the symbolic resources are maintained, offering support for the woman to find explanations to live with the disease which threatens her life, and her identity.

The informants narrated that the family care has provided a meaningful construction when adhering to the treatment and facing the different facets of living with HIV/AIDS. The family is the sweetness of spontaneous care, where they can find affection, desire of cure among the parts, and complicity fighting against the illness. The family is not attached to a reductionist view of what cure is, because when in the social space called "home", the disease is just a disease. Society should never loose such social space, but instead, establish in the family, and not only in the hospital actions, the "art

of cure”⁽¹²⁾.

The healthcare professional needs to distinguish the health-disease process interfaces, which involve both the professional and the person with a disease, as highlighted through I-6 speech. Technology in the health area helped develop knowledge for health professionals, who are, day after day, more capacitated to deal with the disease. Nevertheless, the market place is still lacking of professionals who understand the person with a disease as of what he/she thinks about his/her disease, where culture, individual and collective values and beliefs are present, when the healthcare professional meets the diseased person⁽¹⁸⁾.

The nursing care dealing with HIV/AIDS infected women, either promoting, preventing, treating, rehabilitating, or providing palliative care to them, needs to search for the woman integral dimension. In order to continue the treatment, the informants reported finding strength in motherhood. For women, motherhood is an identity source that lasts for the whole life; women have a maternal function that is a pillar of society and a social fact⁽¹⁹⁾, as it was possible to verify through I-6 and I-5 narrations. In order to continue the antiretroviral treatment effectively, the woman does not worry about death from an individual perspective, but considering her children, who will not have anyone that takes care of them, or maintain their lives; “in this context, her personal projects are not the core concern, but who will assume her social role (...) who will replace her and take care of the children”⁽¹⁹⁾.

The health-disease interpretation cannot be detached from the subjective dimension related to the representations/significations, but related to the individual experience and their social position. Thus, when thinking about the vulnerability of the women who live with HIV/AIDS, we cannot judge based on personal choices, but based on her experience, social location and values she shares, as well as interactions which emerge during the health-disease process, making it a complex experience within its cultural context, beliefs and behaviors^(15-17,20).

CONCLUSION

When analyzing the treatment adherence of women living with HIV/AIDS, the disease is considered part of their daily lives, and of a signification web that is built and maintained in the social living. Understanding the reasons for the treatment adherence by HIV/AIDS infected women leads us to provide inter-subjective care;

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one that is not limited to the disease or the medical resources. Such experience comprehension enables us to provide care related to the family, considering the psychological, social-economic, and cultural aspects.

This care is built in a world where women faces cultural values deeply connected to the disease stigmatization. Adhering to the HIV/AIDS treatment means having it as a part of the women’s daily lives, as a singular experience, for each one experiences the diagnosis acceptance in their own time and space. Upon such reality, professionals involved in the HIV/AIDS Control Program have to be aware that each woman will resignify, and accept the diagnosis to have a more appropriate treatment in their own timing.

The cultural habits and practices in such women’s adherence experiences create strong signification webs to their lives, which help continue with an effective treatment. Therefore, it is necessary that public policy actions create dynamic process solving social-economic problems, so that these women are able to work and have financial resources. In this study, we observed that the women are part of a low income social level. However, they did not allow themselves to give up the treatment; instead, they created a way of escaping intense poverty and continue the treatment within the informal commerce. We leave a suggestion here, so that other initiatives are developed to bring new market place possibilities for HIV/AIDS infected women.

The nursing professionals involved in the HIV/AIDS treatment need to find support in such women’s families for the diagnosis moment. It is absolutely necessary to develop programs and practices to support HIV/AIDS infected women through their families. As verified through the narrations, children, brothers, and partners were allies when supporting the treatment adherence. We should be aware of the fact families can make a difference in the treatment adherence process.

The HIV/AIDS infected woman is dedicated to taking care of her children so as to give her life a new meaning. The reason for continuing the treatment is related to raising her children and watching their physical and cognitive development, as well as protecting them from the difficulties life may bring. It is possible to conclude, therefore, that the mother-child binomial is an important support for an effective adherence.

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