‘I LEAVE IT ALONE AND THEN I GO ON WITH MY LIFE’: MEANINGS OF LIVING WITH HIV FOR MEN IN IRREGULAR ADHERENCE TO ANTIRETROVIRAL THERAPY

“I DEIXO DELA NO CANTO E VOU TOCAR MINHA VIDA”: SIGNIFICADOS DE VIVER COM HIV PARA HOMENS COM ADESÃO IRREGULAR À TERAPIA ANTIRETROVIRAL

“LA DEJO Y VOY A SEGUIR CON MI VIDA”: SIGNIFICADOS DE VIVIR CON VIH EN HOMBRES CON ADHERENCIA IRREGULAR A LA TERAPIA ANTIRETROVIRAL

ABSTRACT

Objective: To describe and analyze the meanings of living with the Human Immunodeficiency Virus (HIV) for men with irregular adherence to Antiretroviral Therapy (ART). Methods: Qualitative research conducted at an ambulatory of a school hospital in Minas Gerais, Brazil, with 10 men. Data was collected from May to September 2011 through semi-structured interview and submitted to content analysis, resulting in the categories “Discovering the HIV infection” and “Living with HIV”. Results: The meanings of living with HIV are distinguished by the coexistence of some misconceptions about HIV/AIDS, consolidated in the epidemic onset, with new perceptions, derived from the gains resulting from use of ART, associated to the valuation of features that bring a sense of non-vulnerability to the man. These aspects can be understood as factors that are directly reflected in the way that the participant men adhere (or not) to ART. Moreover, the limitations imposed by the real conditions of the individuals’ life are highlighted, especially concerning the socioeconomic and cultural context. Conclusion: The process of living with HIV is characterized by complexity, which indicates the planning of health actions from a gender perspective to address the specificities of the masculine universe.

Descriptors: HIV; Acquired Immunodeficiency Syndrome; Men’s Health; Qualitative Research.

RESUMO

Objetivo: Descrever e analisar os significados de viver com o vírus da imunodeficiência humana (HIV) para homens com adesão irregular à terapia antirretroviral (TARV). Métodos: Pesquisa qualitativa, realizada em um ambulatório de um hospital universitário no interior de Minas Gerais, com participação de 10 homens. Os dados foram coletados entre maio e setembro de 2011 através de entrevista semiestruturada e submetidos à análise de conteúdo, resultando nas categorias temáticas “Descobrindo a contaminação pelo HIV” e “(Com)Vivendo com o HIV”. Resultados: Os significados de viver com HIV são marcados pela coexistência de algumas concepções equivocadas sobre HIV/AIDS, consolidadas no início da epidemia, com novas percepções, provenientes dos ganhos advindos da utilização da TARV, associadas à valorização de características que trazem uma percepção de invulnerabilidade pelo homem. Esses aspectos podem ser compreendidos como fatores que se refletem diretamente na forma como os sujeitos aderem ou não à TARV. Além disso, destacam-se também as limitações impostas pelas condições concretas de vida dos sujeitos, principalmente no que se refere ao âmbito socioeconômico e cultural. Conclusão: O processo de viver com HIV caracteriza-se pela complexidade, o que suscita o planejamento de ações de saúde, numa perspectiva de gênero que atenda às specificidades do universo masculino.

Descritores: HIV; Síndrome de Imunodeficiência Adquirida; Saúde do Homem; Pesquisa Qualitativa.
RESUMEN

Objetivo: Describir y analizar los significados de vivir con el virus de inmunodeficiencia humana (VIH) en hombres con adhesión irregular a la terapia antirretroviral (TARV).

Métodos: Investigación cualitativa realizada en un ambulatorio de un hospital universitario en un pueblo de Minas Gerais con participación de 10 hombres. Los datos fueron recogidos entre mayo y septiembre de 2011 a través de entrevista semi-estructurada y sometidos al análisis de contenido resultando en las categorías temáticas “Descubriendo la contaminación por el VIH” y “(Con)Viviendo con el VIH”. Resultados: Los significados de vivir con el VIH son marcados por la coexistencia de algunas concepciones equivocadas sobre VIH/SIDA consolidadas en el inicio de la epidemia con nuevas percepciones provenientes de las ganancias advenidas de la utilización de la TARV asociadas a la valorización de características que traen una percepción de invulnerabilidad del hombre. Eses aspectos pueden ser comprendidos como factores que se reflejan directamente en la forma como los sujetos adhieren o no a la TARV. Además, se destaca también las limitaciones impuestas por las condiciones concretas de vida de los sujetos, principalmente en lo que se refiere al ámbito socioeconómico y cultural. Conclusión: El proceso de vivir con VIH se caracteriza por la complejidad, lo que suscita el planeamiento de acciones en salud en una perspectiva de género que atienda a las especificidades del universo masculino.

Descriptores: VIH; Sindrome de Inmunodeficiencia Adquirida; Salud del Hombre; Investigación Cualitativa.

INTRODUCTION

The increased search for health and adherence to health care services by men – mainly those living with Human Immunodeficiency Virus (HIV) – is a daily challenge in health care facilities. Considering that men’s death rates are higher than women’s,

Studies have showed the low adherence to the treatment.

Masculinity or masculinities are models that help construct men’s identity and influence attitudes, behaviors and emotions that should be followed within a certain culture. Thus, these sociocultural constructions can constitute factors that increase or minimize men’s vulnerability to health risks, as they can get men moving into or out of a self-care life.

Adherence and non-adherence are complex phenomena resulting from the interaction of different factors. The main factors affecting the therapeutic process are the big number of pills, side effects (intolerance), the need for fasting periods, drug incompatibility, the difficulty to understand the therapy goals, the fear of having others discover one’s HIV infection, low education level, low income and current alcohol abuse.

On the other hand, there are factors that can facilitate adherence: the knowledge and understanding of the disease and treatment; the bond with professionals, the team and the health services; social support and knowledge of fundamental rights of people living with HIV.
Regarding men living with HIV, studies have pointed the incompatibility between their working hours and the opening hours of health care facilities, in addition to drug side effects and the influence of the hegemonic masculinity model as factors that contribute to non-adherence to the treatment\cite{10-12,17,19}.

Based on the aforementioned, this study aimed to describe and analyze the meanings of living with the Human Immunodeficiency Therapy (HIV) for men with irregular adherence to the Antiretroviral Therapy (ART).

**METHODS**

This is a qualitative research\cite{20,21} that took place at the outpatient care center of a university hospital located in a city of the Triângulo Mineiro region (Minas Gerais) – a reference for the follow-up of HIV patients. Cases of non-adherence to ART were detected in this outpatient care center, raising questions about the meanings of living with HIV for men and how they can relate this behavior to the treatment.

Men over 18 years old with HIV, who were under medical treatment and indicated for ART with an irregular adherence to it, were invited to participate in the study. In this study, irregular adherence was characterized by unjustified absences to two consecutive consultations and/ or the abandonment of ART within 20 or more days. The study population consisted of ten participants, and it was determined according to the theoretical saturation criteria for qualitative research\cite{21}.

Data were collected through individual semi-structured interviews conducted in a private room or in home visits in the period from May to September 2011. The interviews were digitally recorded and then transcribed.

The interviews were guided by questions related to the general characteristics of the subjects, the process of the discovery of contamination and life with HIV. The subjects were asked to talk about what the treatment is and what they think about it and also the difficulties they face.

Data were analyzed through the thematic content analysis for qualitative research\cite{22}, respecting the following procedures: exhaustive reading of collected material, identification and grouping of similar manifestations into categories, and further discussion. This process resulted into two thematic categories, which articulate empirical data (study objectives and theoretical reference) denominated “Discovering the contamination by HIV” and “(Co) Living with HIV”.

This study was approved by the Human Research Ethics Committee of the Federal University of Triângulo Mineiro (Opinion No. 1837), and interviews were conducted after the subjects read and signed the Free Informed Consent. The participants are hereby identified as interviewees (I1, I2 and so on) in order to assure them of anonymity.

**RESULTS AND DISCUSSION**

The research included ten men aged 33-66 years who have been infected by HIV within a period from 4-20 years. The mean time for diagnosis discovery, according to the subjects’ reports, was 10.77 years and all participants had previously abandoned the ART for more than 20 days. Regarding marital status, four men were married, five were single and one was divorced, and all of them reported having sex with women. A study\cite{14} conducted in Southern Brazil assessed the adherence to antiretroviral drugs in 67 patients aged 24-65 years (mean 41.03) who presented a mean time of diagnosis of 5.8 years.

**Discovering the contamination by HIV**

The first thematic category, which is called “Discovering the contamination by HIV”, approaches aspects relating to men’s adoption of preventive measures in addition to the discussion about participants’ reaction after receiving the diagnosis.

Most participants got infected through, but two got infected for sharing syringes when using drugs. Regarding the individuals who got infected through sex, two aspects related to their self-perception of invulnerability to HIV before infections stand out: the non-use of contraceptive methods in relationships considered stable and the thought that people who looked healthy could not be infected. These aspects can be noticed in the following speeches:

“I lived with a woman who had it (AIDS) and we did not know about it. We separated. As time went by, she got pneumonia and was hospitalized here. That was when she found out and told me about it.” (I3)

“(…) I was married, right? (…) Most of all… I did not even suspected because she was someone you could not imagine (…). At that time, I did not have enough knowledge (…), right? (…) Because when they talked about it, they usually said that the person was deformed, had the flu, lost weight, right? (…) So we (…) looked at someone’s body, something like that, and said ‘no…there is nothing wrong, right? (…) It is not possible’.” (I5)

The direct non-association between the risk of HIV infection and people with a healthy appearance highlights the permanence of conceptions that associate AIDS and HIV infection with “risk groups” and the physical stereotype of a sick person. These conceptions were very common back
in 1980, at the beginning of the epidemic and before the advent of the ART\textsuperscript{(23,24)}, and are not supported by health care services anymore.

In addition to these conceptions, men’s non-adoption of preventive measures concerning Sexually Transmitted Diseases (STDs) in stable relationships increases their vulnerability and gives rise to discussion about how the processes underlying sociocultural constructions of gender influence self-care behaviors.

The term ‘gender’ “refers to the socially constructed roles and definitions and expectations that a particular society considers appropriate for men and women”\textsuperscript{(25)}. Considering that the characteristics of the cultural models of gender socially constitute and validate what is meant to be a man in a certain context (historical, economic and temporal), they cannot be left out of the analysis of AIDS infection/prevention performed by health care professionals.

The subjects’ speeches reveal an association between stable relationships and the non-use of condoms. This aspect has been discussed in a research that assessed scientific production about men and AIDS prevention in the period from 1997 to 2009\textsuperscript{(5)}. In that research, authors say that some barriers to condom use for men may be related to the perception of intimacy between partners and the evidence that such practice symbolically meets attributes that constitute aspects of masculinities that are hegemonically appraised in our culture. Thus, among other aspects, condom use in stable relationships could lead to the questioning of the image of the “good man and faithful husband” who is not afraid to take risks\textsuperscript{(5)}.

However, it is important to highlight that the adoption of preventive measures during sex – mainly those concerning AIDS – is a complex and dynamic phenomenon constituted by culturally valorized (or not valorized) conceptions and processes of subjectification constructed amid concrete life (im)possibilities. In this manner, it is important to highlight health care professionals need to listen to men and problematize their experiences and specificities in order to systematize real effective actions for sexual health promotion\textsuperscript{(5)}.

The moment of diagnosis was marked by the shock and sadness for some interviewees:

“(...) At that time, it was a shock. I have lived like that for six months...” (I2)

Others report that the news about the HIV infection were received naturally:

“(...) Look, I did not get sad or happy, understand? As a normal person...I walked away...gonna take care of it, right?” (I3)

The response to the diagnosis of a particular disease is intrinsically related to the individual’s subjective representation of it. Thus, it is understood that acting “naturally” when receiving HIV diagnosis – an attitude reported by some of the men interviewed in this study – can suggest a change in the representation of AIDS, which would not be directly associated with the condition of fatal disease anymore and has also been evidenced in other studies\textsuperscript{(5,26)}.

Another interviewee highlights the substitution of the initial perception of HIV infection as a fatal disease for its signification as a chronic condition:

“(...) I thought that I would die very fast, that there was no way out, but then I saw it was not like that, right? (...)” (I7)

This perception is corroborated by the other interviewees who, despite reporting several difficulties in living with HIV, pointed the need to carry on with life despite the disease:

“(...) I (laughs) leave her alone and carry on with my life, and I keep going...” (I7)

It is important to highlight that the representation of AIDS as a chronic condition, which is also problematized in other studies\textsuperscript{(5,26)}, associated with the non-perception of the chances of getting infected through sex with apparently healthy people, can be a factor that increases men and women’s vulnerability to HIV.

An aspect that has called attention in the speeches was the relation established by other interviewees between diagnosis and the period in life it came out. In adolescence, it has an impact that is bigger than that of adult life due to the bigger life expectancy. This can be noticed in the following speeches:

“Oh, it was difficult, because I was in adolescence, right? (...) It was very hard [...] to get information, treatments to live longer...” (I8)

“(...) I did not care about it because [...] I was over fifty [years]; I was already at the end of life. If I were an 18-year-old adolescent, ok, there would be much to live. But I was not, so I did not care about it.” (I4)

This perception may relate to the representation of HIV/AIDS infection as a chronic disease, which has already been discussed, and it is in accordance with studies that
have shown an increase in the infection incidence among older people, including elders\(^2\(^3\).\)

\((\text{Co})\text{Living with HIV}\)

The contents regarding the process of living after an HIV diagnosis are discussed in the thematic category “(Co)living with HIV”. The data of this category reflect individual, social and programmatic factors that influence the meaning of living with HIV and constitute the different situations of vulnerability that can aggravate the health status of the participants, mainly with regard to men’s (im) possibilities to effectively adhere to the ART.

When asked to talk about the changes due to HIV infection, the subjects pointed physical changes due to opportunistic diseases, sleep and humor disorders, and, mainly, the occurrence of depressive symptoms:

“(...) I had many small tumors in the brain caused by the disease.” (I6)

“(...) It [the disease] causes psychological effects. It was hard.” (I8)

In addition to that, the interviewees reported the changes in daily routine due to the need for preventive measures to avoid the infection by other diseases. This can be seen in the following speech:

“(...) I do not drink coffee or anything at the bar because I am afraid of drinking from someone else’s glass... Because of hepatitis. I have HIV, getting hepatitis would be fatal...” (I2)

HIV diagnosis makes people think about their behavior patterns, beliefs and values. The reflection can trigger changes in individual behaviors and hence decrease the vulnerability to getting sick\(^1\(^5\).\) As observed during interviews, other studies show that keeping healthy nutrition and habits and reducing the exposure to other infectious and contagious diseases – since they directly interfere with the treatment/care – are strategies adopted by some infected people\(^2\(^6\)\(^,\)\(^2\(^7\).\)

Still with regard to the impact of HIV on life’s trajectory, the restrictive changes in the establishment and maintenance of love and sexual relationships stand out since men started being afraid of infecting other people. This is reported below:

“(...) I had many relationships, girlfriends, right? I definitely had to turn my back on these people because it goes like this: it was starting to get dangerous, we were starting to like each other for real... When it was time to get laid or live together with that person, I had to turn my back on this person and leave...” (I3)

The changes related to sexual and reproductive life of HIV people have been analyzed by researchers who pointed the little information about the affective and sexual life of these people provided by HIV/AIDS specialized services\(^2\(^9\).\)

The existing public policy about sexual and reproductive rights theoretically include all individuals, including people with infections and chronic diseases\(^2\(^8\).\) However, with regard to the sexuality of people with HIV, there is prejudice and stigma resulting mostly from the construction of the ideas of “risk group” and “transmission”, which were spread in the moment people found out about AIDS\(^2\(^9\).\)

Thus, it is believed that the planning of sexual and reproductive health actions for this group cannot only be subsidized by statistics of HIV infection probabilities. They should include the understanding of subjective processes that involve the experience of sexuality in the real life contexts of the subjects.

Another aspect pointed by the interviewees of this study was the impact of prejudice as it is highlighted below. Studies show that the prejudice is one of the main worries of infected people and favors the low adherence to treatment\(^1\(^3\)\(^,\)\(^1\(^7\)\(^,\)\(^2\(^7\)\(^,\)\(^2\(^9\).\)

“(...) And the prejudice never ends, right? (...) You unintentionally change your glass; you unintentionally change your plate; you unintentionally change your fork; unintentionally, people do not lend you a t-shirt; unintentionally, they do not want anything from you too. So, this is boring; it’s something that hurts, you know?” (I3)

The interviewees reported hiding the disease from their social groups due to the fear of suffering prejudice from friends and family members, and also the fear of being dismissed from work.

“(...) No, if we tell about it, they will put us out...” (I7)

“(...) Oh, she [mother] would not react in a good way, because she is an old fashioned person, right? (...) Old system, so they do not accept it, right? (...) There is prejudice.” (I5)

On the other hand, the subjects highlight the social support represented by the care received from partners and/ or family members as the main basis for facing life with HIV.

“(...) It is essential. During the treatment... if all the family can participate is better, it is easier. It gets easier for us...
because the seropositive patient needs affection too, and the family is the most important thing…” (I8)

It is understood that the fear of prejudice and isolation leads seropositive individuals to avoid disclosing the diagnosis to family members and partners, limiting their life and social support.(30)

Actions to expand the social network for the support of people with HIV are very important, but they go beyond the structuring of health care facilities as places for exchanges and learning among individuals, and as social and emotional dimensions of life with HIV. The constitution of these places should follow the establishment of interventions directed to the whole society, contributing to the deconstruction of historically and culturally built conceptions that sustain the social stigmatization around AIDS/HIV.

These strategies are important because social support and availability increase patients’ survival, soothing suffering and contributing to a successful treatment, which reduces the pathogenic effects of stress on the organism and enhances people’s capacity to cope with difficult situations and to reorganize their lives.(13,17,30,31)

In this current study, the factors that influence and relate to men’s irregular adherence to the ART stand out. All the interviewees characterize the HIV treatment by the medical consultation frequency:

“Oh...for me it’s ok. I attend the consultation, get my medicines, take them at home...” (I8)

The interviewees gave much importance to the treatment, and they even associated the use of medicines with the possibility to continue living:

“(…) I can’t keep on playing with life, oh no, right?” (I3)

However, it is important to highlight that unlike the rational valorization of the treatment, all the participants in this study presented attitudes of irregular adherence to the ART during some periods. This unanimous conception, which associates the HIV treatment with medical consultations and the use of ART and is corroborated by the lack of mentions of other care approaches provided by other professionals as psychologists, nurses, occupational therapists, nutritionists, social assistant, among others, entails the need for some reflections.

First, the research participants’ characteristic, reflected in behaviors of irregular adherence, can relate to the unawareness or the failure to recognize approaches that are complementary to the medical treatment. It is important to consider the possibility of little provision of these services for the people, reflecting aspects of the programmatic dimension(30) (the role health care, education and other institutions play in the vulnerability process of individuals and social groups) of the experienced vulnerability, which can be aggravated by attitudinal matters of the health care team.

With regard to doctors’ attitudes, a study(32) showed that the viral load tests take most of the time of consultations and that doctors do not often assess subjective aspects of patients. On the other hand, by analyzing patients’ perceptions, researchers point that the examinations are characterized as a way to notice the disease in a clear and concrete way, and patients believe that doctors could only help them through the examinations.

The evolution of examinations and medicines for AIDS/HIV control brought invaluable advancements for the survival and quality of life of infected people. However, there is a need to expand the spectrum of the care received by this population, as it has been observed in this study, in which the participants presented contradictions regarding the perception that the treatment is important (sometimes vital) for their lives and the non-adherence to it. This expansion should start from both people living with HIV and professionals’ perception of health as a condition that is beyond biological aspects; they should develop interdisciplinary actions to approach multiple biopsychosocial aspects, which would result in improvements added to the benefits from medical care.

When asked about the difficulties for adhering to treatment, the interviewees highlighted that problems related to work and their financial situations are barriers that prevent them from attending medical consultations (performed monthly). With regard to work, they highlighted the incompatibility between their working time and the opening hours of health care facilities, which makes them miss their work in order to go to the doctor.

“(…) I can’t keep leaving the work like that. It slows down my work, so…” (I9)

In addition, these people face precarious economic conditions that prevent them from attending medical consultations and, sometimes, hinders the adherence to the medicines. The interviewees reported the impossibility to afford transportation to the consultation and, sometimes, the expenses of the treatment – as the costs to keep a good nutrition.

“(…) Sometimes you have money to keep your home, your food, because the medicine you take is very strong, and
you have to be nourished. So, you have to eat something, let’s not say better, but you must have veggies, meat, normal food to take the meds. So, sometimes the consultations are scheduled to the end of the month, you have no money, you either come on foot or stay home. It’s very hard…” (I8)

The incompatibility between work and visits to health care facilities has also been observed in other studies(11,33,34) aiming to understand questions relating to men’s health. They bring the hegemonic conception of men providing material for their family as one of the reasons that impede the search for preventive methods and health care. Additionally, researchers agree about the need to change the opening hours and the dynamics of health care facilities in order to meet working men’s needs.

However, in addition to these factors, this study highlighted the extreme poverty and social vulnerability faced by the participants, showing that health care professionals should reflect about the need to develop effective intersectoral actions aiming to ensure the access to health, which is a basic social right.

Regarding the difficulties in the use of ART, most interviewees highlighted the occurrence of side effects like vomiting, malaise, sleepiness and also the quantity and routine of use of medicines.

“(…) There is this concern about the time, right…you can’t forget to take the meds. You must take it in the morning, at lunchtime, and at dinnertime. Lunchtime, in the morning and dinnertime…I mean, it’s part of it; it’s already part of your life…” (I3)

The results of the current research are in accordance with other studies on factors that interfere with good adherence to medicines, regardless of gender. The main factors are: big quantity, drug incompatibility, difficulties to understand the therapy goals, times to take the medicines, unpleasant smell and flavor, forgetfulness, discouragement, interruption to drink alcohol, lack of trust in the treatment, unsatisfactory orientation, lack of trust in the doctor, complexity of treatment, some medicines need to be taken with food and others under fasting, the fear of having other people find out about their condition and the difficulty to dissolve or swallow the pills(11,26,27,29).

The difficulties concerning the use of ART found in this study highlight the HIV person’s decision to change lifestyle in order to manage and accept certain side effects; they also show that the health care team needs to perform supporting actions that bring positive specific contributions to the life of everyone.

However, the interviewees of this study pointed the forgetfulness or the stop in the use of ART as an attitude of negligence or voluntarily assumed.

“(…) I wanted to stop the treatment, I didn’t care about the medication anymore, I abandoned everything…” (I8)

In addition to this, the individuals’ speeches highlight the use of alcohol and/or other drugs as factors that sometimes impede the use of medicines.

“(…) Most men fear the doctor because they drink. I myself was stubborn, but I used to hit the bottle… The medicines didn’t work…right?” (I9)

The use of illicit drugs and/or alcohol is considered a barrier to the adherence to HIV treatment, and it negatively influences the whole therapeutic process(11,14,21,29). This aspect points to the need for interventions subsidized by the principle of comprehensive care for the user of the Brazilian National Health Care System. These interventions should take into account the gender specificities and articulate actions aimed at approaching drug addiction and HIV/AIDS treatment.

**FINAL CONSIDERATIONS**

In general, the analysis of the meanings of life with HIV brought to light the need to understand this process, because individual aspects that constitute the subjectivity of each participant articulate, change and are changed by factors constructed in the cultural, social and economic experience. This complexity is clearly highlighted by the evidence of contradiction between the rational valorization of the importance of treatment and attitudes that characterize the irregular adherence to it.

The meanings of living with HIV for the participants of this study are permeated by the coexistence between some mistaken conceptions – consolidated at the beginning of the epidemic – and the valorization of aspects that characterize man as strong and invulnerable person. These aspects can be understood as some of the factors that influence the way men adhere to the use of ART. Besides that, this study showed that the use of psychoactive substances and the concrete conditions of life – mainly economic and cultural ones – can influence men’s (im)possibilities to take care of their health.

This context made possible the observation of manifestations, in different dimensions (individual, social and programmatic), of men’s vulnerability to HIV.
This current study faced some difficulties to its conduction as the location of subjects and scheduling of interviews (due to the irregular adherence to the service). Although they cannot be generalized, this study pointed aspects that show that health care professionals should reflect about the different aspects affecting men’s (im) possibilities to effectively adhere to the use of ART.

In this sense, this study states the need for the planning of interventions that bring men and health care facilities together and culminate in stimulating strategies, consolidating the valorization of aspects like self-care and the adoption of preventive measures in men’s life.

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