

Antiretroviral therapy: compliance level and the perception of HIV/Aids patients

Terapia com antirretrovirais: grau de adesão e a percepção dos indivíduos com HIV/Aids
Terapia con antirretrovirales: grado de adhesión y percepción de individuos con VIH/SIDA

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Descritores

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Abstract

Objective: Understand the aspects related to HIV/AIDS patients' compliance level with antiretroviral drugs.

Methods: Qualitative study developed at two inpatient units of a university hospital in the interior of the State of São Paulo, Brazil. The data were produced between October 2017 and April 2018, interviewing 40 participants. The produced material was recorded and later transcribed. For the data analysis and processing, the Descending Hierarchical Classification technique was used for support, in the framework of the Collective Subject Discourse.

Results: After the analysis and processing, five word classes resulted: 1. Socioeconomic aspects as fundamental reasons for non-compliance with antiretrovirals; 2. Family support to cope with the condition and stimulate treatment compliance; 3. Consequences of the compliance level with antiretrovirals; 4. Difficulties to comply with antiretroviral therapy related to adverse effects and medicine format; and 5. Possible changes to improve compliance with HIV treatment.

Conclusion: The main difficulties people living with HIV/AIDS who are hospitalized and with irregular compliance face are socioeconomic aspects, family support and adverse effects.

Resumo

Objetivo: Aprender os aspectos relacionados ao grau de adesão de pessoas vivendo com HIV/aids aos antirretrovirais.

Métodos: Estudo com abordagem qualitativa desenvolvido em duas unidades de internação de um hospital universitário do interior paulista. A produção dos dados ocorreu no período de outubro de 2017 a abril de 2018 com 40 participantes entrevistados, cujo material produzido foi gravado e posteriormente transcrito. A análise e o processamento dos dados foram realizados com apoio na técnica da Classificação Hierárquica Descendente e base fundamentada no Discurso do Sujeito Coletivo.

Resultados: Após análise e processamento, obtiveram-se cinco classes de palavras: 1. Questões sócio-econômicas como motivos fundamentais da não adesão aos antirretrovirais; 2. O apoio familiar para o enfrentamento da condição e estímulo para a adesão ao tratamento; 3. Consequências do grau de adesão aos antirretrovirais; 4. Dificuldades de adesão à terapia antirretroviral relacionadas aos efeitos adversos e apresentação medicamentosa; e 5. Possíveis mudanças para melhorar a adesão ao tratamento do HIV.

Conclusão: As principais dificuldades enfrentadas por pessoas vivendo com HIV/aids hospitalizadas e que estão em adesão irregular são questões sócio-econômicas, apoio familiar e efeitos adversos.

Resumen

Objetivo: Comprender los aspectos relacionados al grado de adhesión de personas afectadas por VIH/SIDA a los antirretrovirales.

Métodos: Estudio con abordaje cualitativo, desarrollado en dos unidades de internación de un hospital universitario del interior paulista. Datos producidos de octubre de 2017 a abril de 2018 con 40 participantes entrevistados, cuyo material fue grabado y posteriormente transcrito. El análisis y procesamiento de datos se realizó con apoyo de la técnica de Clasificación Jerárquica Descendente, y la base, fundamentada en el Discurso del Sujeto Colectivo.

Resultados: Analizados los procesos, se obtuvieron cinco clases de palabras: 1. Cuestiones socioeconómicas como motivos fundamentales de no adhesión a los antirretrovirales; 2. Apoyo familiar para enfrentar la condición y estímulo para adherir al tratamiento; 3. Consecuencias del grado de adhesión a los antirretrovirales; 4. Dificultades de adhesión a la terapia antirretroviral relacionadas a efectos adversos y presentación de los medicamentos; y 5. Posibles cambios para mejorar la adhesión al tratamiento del VIH.

Conclusión: Las principales dificultades enfrentadas por personas afectadas por VIH/SIDA hospitalizadas y en adhesión irregular las constituyen cuestiones socioeconómicas, apoyo familiar y efectos adversos.

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Introduction

In the last 30 years, the AIDS (acquired immunodeficiency syndrome) epidemic has entailed negative consequences for families, communities and countries, representing one of the greatest contemporary challenges to public health. More than 7,000 people are infected with the Human Immunodeficiency Virus (HIV) every day.⁽¹⁾ Globally however, its transmission has declined by 16% since 2010 as a result of prevention and treatment programs.⁽²⁾

About 36.7 million people are living with HIV/AIDS worldwide, with approximately 1.8 million new cases registered in 2016.⁽²⁾ Since the beginning of the epidemic in Brazil, from 1980 to June 2017, 882,810 cases of AIDS have been registered, with an average of 40,000 cases annually in the last five years.⁽³⁾

In order to address the problem, Brazil guarantees universal and free access to antiretrovirals through the Unified Health System (SUS).⁽⁴⁾

The 90-90-90 target, created by the United Nations program that contributes to end the AIDS epidemic worldwide,⁽⁵⁾ sets forth that 90% of people living with HIV/AIDS (PLHA) be aware of their diagnosis, 90% already under treatment and 90% with an undetectable viral load. In Brazil, according to data for 2015, 60% of PLHA are being treated and approximately 54% are in viral suppression.⁽²⁾

Although access to antiretrovirals is free in Brazil, advances are still needed to achieve the goals of the 90-90-90 target. The distribution system of the therapy in the country is a prominent model in the international scenario, especially due to the universality of access.⁽⁶⁾

The objectives of antiretroviral therapy (ART) are to reduce morbidity and mortality and improve people's quality of life through viral suppression, which permits delaying or preventing the development of immunodeficiency.⁽⁷⁾ Intermittent treatment is necessary though. In fact, ART changed the scenario of the problem, significantly reducing morbidity and mortality.^(8,9)

A meta-analysis on ART in Latin America and the Caribbean showed a 70% compliance rate in the 25 countries surveyed. The following barriers to compliance were identified in the study: use of al-

cohol and other drugs, factors related to depression, unemployment and the number of tablets recommended in the therapy.⁽¹⁰⁾

In view of the above, further investigation is needed of what permeates the compliance with antiretrovirals of people living with HIV/AIDS. Based on the above considerations, the objective of this study was to understand the aspects related to the level of compliance of HIV/AIDS patients with antiretrovirals.

Methods

Qualitative research based on the collective subject discourse method, which is established in key expressions, structured and determined for the formation of essential ideas and similar to the participants' discourse, permitting the establishment of collective thinking.^(11,12)

In total, 40 people living with HIV/AIDS participated in the study and were hospitalized at a referral hospital in an interior city in the state of São Paulo, with medical records of irregular compliance with antiretrovirals. Participants were selected by convenience sampling and met the inclusion criteria, namely: being 18 years of age or older, being aware of the diagnosis of AIDS and presenting pick-up rates of antiretroviral drugs inferior to 80% in the past 12 months in the Logistic Control system of Medicines (SICLOM), according to available evidence.⁽¹³⁾

Those in confinement situations (inmates and institutionalized patients) and those with undetectable viral load as reported in the electronic medical record were excluded.

The data were collected from October 2017 to April 2018, with completion based on theoretical saturation criteria. We conducted in-depth interviews with an average duration of 30 minutes, in a private room, guided by a semi-structured tool with open questions about compliance with antiretrovirals. The participants' discourse was recorded and later transcribed for the creation of a textual corpus.

The data were processed in IRaMuTeQ (R INTERFACE for multidimensional analysis of texts and questionnaires) by means of lexical analyses. The co-occurrences of words were calculated

that permit identifying topics of interest for the investigation. For the analysis of the textual data, the descending hierarchical classification (DHC) method was followed.⁽¹⁴⁾

After processing the data, classes predefined by the software were obtained, based on the organization of the most significant vocabulary in thematic axes. Then, the key expressions in the participants' discourse were organized to complement the CHD and to name the definitive classes based on the words contained in the CHD and the excerpts from the discourse.

The research received approval from the Research Ethics Committee of the University of São Paulo at Ribeirão Preto College of Nursing, CAAE: 57372416.7.0000.5393. The ethical premises for research involving human beings were complied with. All participants signed the Free and Informed Consent Form.

Results

In total, 40 people living with HIV/AIDS were included in the study, with a mean age of 41 years (median ± 42.62 / standard deviation ± 12.51) and mean HIV diagnosis time of ± 13.4 years (median 10 years / standard deviation ± 7.69).

Among the study participants, 17 (42.5%) were cisgender men, 21 (52.5%) cisgender women and 2 (5%) transgender / transsexual women. As for education, 7 (17.5%) were illiterate, 13 (32.5%) had not finished elementary education, 14 (35%) finished elementary school, 5 (12.5%) finished high school and 1 (2.5%) finished higher education. Twenty four (60%) gained an income, 26 (65%) had children and only 10 (25%) had active sexual partners. Regarding family support, 70% (30) reported having support.

In the processing of the statement, IRaMuTeQ recognized 39 initial context units (ICUs), 424 elementary context units (ECUs), and 15,180 occurrence records. The usage rate of the textual corpus was 80.42%. Based on the Descending Hierarchical Classification (DHC), the most relevant and most reported words were analyzed.

Five classes were obtained through the analysis: 1 - Socioeconomic issues as fundamental reasons for non-compliance with antiretrovirals; 2 - Family support to cope with the condition and stimulate treatment compliance; 3 - Consequences of irregular compliance with antiretrovirals; 4 - Difficulties of regular compliance with antiretroviral therapy, related to adverse effects and drug format and 5 - Possible changes to improve compliance with HIV treatment. These classes were identified in key terms and displayed in the final tree diagram (Figure 1).

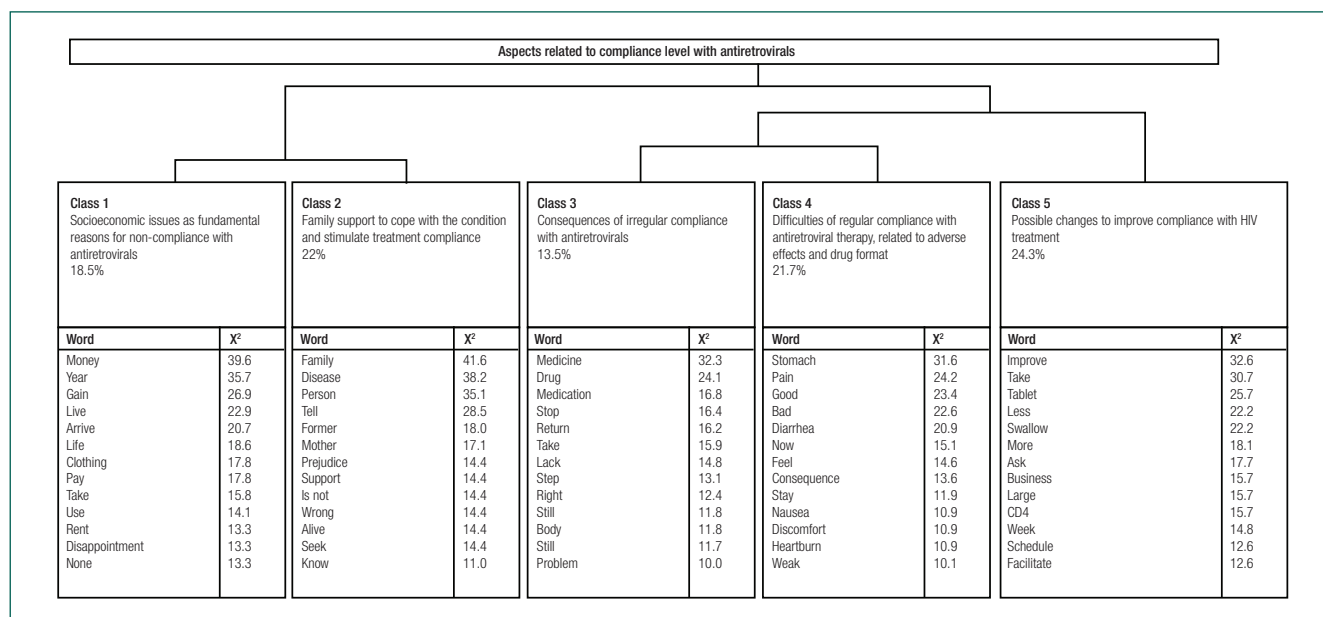


Figure 1. Graphical representation of aspects related to irregular compliance with antiretrovirals

Class 1: Socioeconomic issues as fundamental reasons for non-compliance with antiretrovirals

In this class, patients reported difficulties related to noncompliance with antiretrovirals, with emphasis on the lack of financial resources and drug use. Others reported that they stopped using antiretrovirals because they did not care about the correct time or forgot.

It is highlighted that the relevance of achieving maintenance and/or financial stability surpasses the concern with the clinical condition so that treatment is pushed to the background.

"I stopped on my own, because they were nauseating me and I needed to work". E-09

"I worked at night and stopped working because the back that was already rotting, it did not function anymore, so nobody helps me, I do not have social assistance". E-14

"I used drinks and drugs along with the medicines, so when I used them I did not take the medicine". (E-16)

"Sometimes, for example, if I missed the medication time, I did not worry. I was not going to run away and I did not have medicine in my pocket". (E-24).

In the case of some narrations, the discouragement with the treatment and having to deal with the disease daily entails giving up the therapy:

"I've been here so many times. I go there and stop and come back here again; laziness also, I am tired already of this patient life". (E-31)

Class 2: Family support to cope with the condition and stimulate treatment compliance

The participants reported social problems related to the disease. On the other hand, they also emphasized the importance of the family in the treatment process. It is known that family support for the treatment improves compliance with antiretrovirals significantly, as it highlights their relevance to the family group. In some cases, revealing the diagnosis to family and friends may have negative outcomes. Negative experiences can be observed:

"I told about my condition (to the affective partner) and it was very traumatic because I ended up being rejected, I even panicked". (E-35)

"A bit of family support too, lack of support. I come from the doctor and no one asks how my tests are, that's also what hurts me". (E-31)

Class 3: Consequences of irregular compliance with antiretrovirals

In this class, the consequences of abandoning the antiretrovirals were evidenced. The participants believe that the fact that they are hospitalized is somehow related to the interruption of treatment. The clinical symptoms were the most recurrent, considering that there is a drop in the count of defense cells of the immune system, making the patient susceptible to other diseases, mainly opportunistic conditions secondary to HIV.

"I'm here today because I got weak legs, shortness of breath, a problem in the lung, which is tuberculosis". (E-08)

"Because it's the third time I've changed the cocktail because I've stopped and come back, but it's the first time it hits one of my organs in 17 years". (E-13)

"I think this urine infection I had, which is already the third time, and the weakness is because I stopped with the medicine". (E-33).

Class 4: Difficulties of regular compliance with antiretroviral therapy, related to adverse effects and drug format

The amount and size of the tablets were noted as obstacles to regular treatment compliance. In addition, clinical manifestations such as epigastralgia, nausea and emesis predominate in this class and are strongly interconnected to reasons for poor compliance; as observed:

"I was taking those little ones that did me no harm then he came back with those huge ones he'll finish me off". (E-20)

"The size of the medicines and their effects, it destroys the stomach because they cure one thing and harm another". (E-04)

"I have a weak stomach for medicine in general and I have to take a medicine to be able to take the cocktail that harms me, it harms me a lot". (E-25)

"I stopped drinking because I cannot even see the bottle of medicine, just seeing the bottle already upsets my stomach". (E-33)

Class 5: Possible changes to improve compliance with HIV treatment

The participants pointed to aspects that may contribute to improve the compliance with HIV treat-

ment. Most indicated the use of smaller tablets and therapeutic regimens with fewer tablets for ingestion.

"If it were small I could even take it, but those huge tablets [...]". (E-06)

"Big pills that made me vomit, if it were less medicine and smaller, because I take 04 pills" (E-08).

"Something liquid because it does not hurt the stomach so much, you see, and it is easier to swallow" (E-21).

The irregular treatment compliance evidenced in this study is a source of concern, as the mean time of the participants' HIV diagnosis is little more than 13 years and it is expected that, the longer the diagnosis and treatment, the better the compliance with the antiretrovirals as a result of the routine.

It was observed that the five classes present relevant content to understand the irregular compliance with the HIV/AIDS treatment and can broaden the understanding of the subjectivities of the PLHA that involve the perception about their condition and the need for treatment.

Understanding these issues can contribute to the health professionals' practice, guiding them towards a broader approach to each individual's needs in an individualized way. The participants point out financial conditions, drug use, family support and difficulties with drug formats as factors to be considered.

Those factors influence the regular compliance with antiretroviral therapy. One of the great challenges the professionals involved in the care for these patients face is to develop strategies that are sensitive to the subjectivities of PLHA and that are capable of producing positive results in improving treatment compliance.

Discussion

It was identified that irregular compliance with antiretrovirals is related to aspects of the social, economic and cultural context of PLHA. Although the treatment in Brazil is free, the financial issues mentioned entail strong implications in daily social life and exert influence in the regular use of the

medicine. Other conditions were reported: need for family support; use of alcohol and other drugs and difficulties to adapt to the drug format.

The HIV/AIDS therapy alone is a major challenge and adds up to the individual and collective aspects of PLHA. The complexity of the therapeutic scheme and the reactions to the medicines can be highlighted. In this sense, to manage the compliance, multiple factors need to be considered.⁽¹⁵⁾

Regarding the financial problems, there is evidence in the literature that the employment and income situation is a significant factor associated with non-compliance with the treatment.⁽¹⁶⁾ In order to achieve better outcomes in antiretroviral treatment, managers and health professionals need to consider situations that pervade the free distribution of medicines, such as the sociocultural context the PLHA are inserted in. Efforts are needed to identify the difficulties in regular compliance with antiretrovirals, so that interventions capable of promoting positive change can be carried out.

Another highlight was the lack of family support, which the participants characterized as relevant for decision making on treatment abandonment. Studies show that the family exerts strong influence on treatment compliance, which goes beyond the financial aspect. The lack of emotional support and absence of family care were identified in a study involving people who abandoned HIV/AIDS treatment in Rio de Janeiro.⁽¹⁷⁾

Fear of being abandoned by the family as a result of the diagnosis of HIV infection is directly associated with treatment compliance.⁽¹⁸⁾ Indeed, emotional support from the family to cope with the new condition is relevant at different times in the PLHAs' life, both for the acceptance of the diagnosis and the perception of the need to initiate the treatment and conduct it consistently.

As for alcohol and other drugs, the significant association between substance use and non-compliance with treatment was noteworthy in another study.⁽¹⁶⁾ Similar results involving alcohol consumption were found among adolescents living with HIV in Malawi.⁽¹⁹⁾

Research in different realities has already shown that alcohol use decreases compliance with

antiretrovirals.⁽²⁰⁻²²⁾ The reports obtained in this study demonstrate that participants decided to discontinue treatment to consume alcohol and/or other drugs.

Forgetfulness was one of the justifications for irregular compliance pointed out in this research. Another study showed that 32.9% of the subjects presented forgetfulness as the main cause of non-compliance.⁽²³⁾ A study conducted in South Korea between 2006 and 2015 found that 30% of the participants stopped taking antiretroviral drugs more than once month due to forgetfulness.⁽²⁴⁾

In addition to the difficulties identified, the consequence of irregular compliance stand out, such as the drop in defense cells and the hospitalizations due to the worsening of the health condition. The immune system of ART users who do not comply with the treatment properly gets damaged, reflected in low levels of TCD4+ lymphocytes and, consequently, the progression towards Aids and the increased chance of opportunistic infections.^(25,26)

As for difficulties to regularly comply with the antiretroviral therapy related to the adverse effects and medicine formats, in a Brazilian study, it was identified that, in a sample of PLHA, 24% of the participants reported adverse events.⁽²⁷⁾ In a study developed in East Africa, the presence of adverse effects negatively influence the antiretroviral therapy⁽²⁸⁾ and can affect different areas of human beings, ranging from the physical to the psychosocial.⁽²⁹⁾

Possible changes to improve compliance with HIV treatment identified in this study were supported by an international study,⁽³⁰⁾ in which individuals undergoing injectable antiretroviral therapy reported better compliance due to the monthly or six-monthly application regimen.

A limitation in this study is that only people were investigated who were hospitalized due to the health complications the irregular compliance with the antiretrovirals had caused. Hence, PLHA who did not experience health complications and who for some reason were not hospitalized were left out. This means that people in other health conditions were not included in this research.

Conclusion

The main difficulties HIV/aids patients in hospital and showing irregular compliance with ART are socioeconomic and family support issues and the adverse effects of the treatment. The five classes present contents that contribute to understand the irregular compliance with the HIV/aids treatment and can guide the health professional's practices towards a comprehensive approach of the person's particularities.

Collaborations

Freitas JP, Sousa LRM, Cruz MCMA, Caldeira NMVP and Gir E declare that they contributed to the Project design, data analysis and interpretation, relevant critical review of the intellectual content and approval of the final version for publication.

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