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RESEARCH

MENTAL SUFFERING, HOPELESSNESS, AND ADHERENCE TO ANTIRETROVIRAL THERAPY OF PEOPLE WITH HIV/AIDS

SOFRIMENTO MENTAL, DESESPERANÇA E ADESÃO A TERAPIA ANTIRRETROVIRAL DE PESSOAS COM HIV/AIDS

SUFRIMIENTO MENTAL, FALTA DE ESPERANZA Y ADHERENCIA AL TRATAMIENTO ANTIRRETROVIRAL ENTRE PACIENTES CON HIV/ SIDA

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ABSTRACT

Objective: to analyze the association between mental suffering, hopelessness, age, and education when adhering to antiretroviral therapy for people with HIV/AIDS. **Method:** Cross-sectional study conducted from January to July 2019, at a reference hospital for infectious diseases in the Northeast, Brazil. Participated 100 people with HIV/AIDS who responded to the scales of mental suffering, hopelessness, and adherence to antiretroviral therapy (CEAT-HIV). Descriptive statistical analysis and Kruskal Wallis tests, t Test, chi-square, and MannWhitney, considering significance when p≤0.05. **Results:** it was identified that 64% were men, 50% had completed elementary school, 58% had mental distress, 48% mild hopelessness, 60% had difficulty in treatment with antiretroviral therapy. **Conclusion:** the results revealed that hopelessness is associated with adherence to antiretroviral therapy; mental suffering is associated with the hopelessness score; age is associated with the score of mental suffering, hopelessness, and adherence to antiretroviral therapy.

Keywords: Depression; Anxiety; HIV; Mental Health.

RESUMO

Objetivo: *analisar aassociação entre sofrimento mental, desesperança, idade e escolaridade na adesão à terapia antirretroviral de pessoas com HIV/AIDS.* ***Método:*** *Estudo transversal realizado de janeiro a julho de 2019, em Hospital referência para doenças infectocontagiosas no Nordeste, Brasil. Participaram 100 pessoas com HIV/AIDS que responderam às escalas de sofrimento mental, desesperança e adesão à terapia antirretroviral (CEAT-VIH). Análise estatística descritiva e testes Kruskal Wallis, teste t, qui quadrado e Mannv Whitney, considerando significância quando p≤0,05.* ***Resultados:*** *identificou-se que64% eram homens, 50% possuíam ensino fundamental completo, 58% apresentavam sofrimento mental, 48% desesperança leve, 60% tinham dificuldade no tratamento com terapia antirretroviral.* ***Conclusão:*** *os resultados revelaram que a desesperança está associada à adesão à terapia antirretroviral; o sofrimento mental está associado ao escore de desesperança; a idade está associada ao escore de sofrimento mental, desesperança e adesão à terapia antirretroviral.*

Palavras-chave: *Depressão; Ansiedade; HIV; Saúde Mental.*

RESUMEN

Objetivo: *analizar la asociación entre el sufrimiento mental, la falta de esperanza, la edad y la escolaridad en la adhesión al tratamiento antirretroviral de personas con HIV/SIDA.* ***Método:*** *estudio transversal realizado de enero a julio de 2019 en un hospital de referencia para enfermedades infectocontagiosas del noreste de Brasil. Participaron 100 personas con HIV/SIDA que respondieron a las escalas de sufrimiento mental, falta de esperanza y adherencia al tratamiento antirretroviral (CEAT-VIH). Análisis estadístico descriptivo y pruebas de Kruskal Wallis, prueba t,*

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chi cuadrado yMannv Whitney, considerando significancia cuando p≤0,05. ***Resultados:*** *se identificó que64% eran hombres, el 50% había terminado la escuela primaria, el 58% sufría de angustia mental, el 48% sentía ligera falta de esperanza, el 60% dificultad en el tratamiento antirretroviral.* ***Conclusión:*** *los resultados señalan que la falta de esperanza está asociada con la adherencia a la terapia antirretroviral; el sufrimiento mental está asociado con el escore de falta de esperanza; la edad está vinculada con el puntaje de sufrimiento mental, falta de esperanza y adherencia a la terapia antirretroviral.*

Palabras clave: *Depresión; Ansiedad; VIH; Salud Mental.*

INTRODUCTION

AIDS is considered a worldwide epidemic and, despite technological advances and health actions developed globally, aiming at disease prevention and adherence to antiretroviral therapy (ART), data on the incidence of people with the infection are still alarming. Estimates suggest that at the end of 2019 the number of people in the world living with HIV/AIDS was 38.0 million. Of these, only 68% of adults and 53% of children received ART.[1]

In Brazil, 996,058 AIDS cases were reported in the 39-year period (1980 to June 2019), in addition, it was one of the first countries among the underdeveloped countries to offer free treatment to people living with HIV/AIDS.[2]

Living with a chronic illness such as HIV/AIDS, which is still stigmatized and which causes various physical and psychosocial changes, can lead the individual to present psychological distress.[3] A study conducted with 200 HIV-positive individuals in Pakistan showed the existence of a significant relationship between suicidal behavior and mental suffering in people living with HIV/AIDS, distancing them from well-being, compromising HIV coping strategies.[4]

The impact on me ntal health is common due to the feeling of guilt in relation to infection, the concern to communicate to the family and coping with prejudices in the family and social context, making the individual weakened.[5] Positive HIV diagnosis is still associated with fear, isolation, indifference and distance from family, friends and partners, making what would be a contribution to treatment a barrier about positive diagnosis, inhibiting access to the necessary health resources.[6]

After the discovery of HIV infection, the feeling of hopelessness arising from concerns about the evolution of the disease, fear of dying, insecurity and pessimism may emerge in the individual. To this end, there are several helpful mechanisms to face this feeling, such as religion, family support, psychotherapy, self-help groups and qualified multiprofessional assistance, such as Nursing.[7]

Hopelessness involves the lack of belief in better days, the impossibility of success and achievement of goals, in addition to not solving problems, contributing to the non-adherence to ART.[7] However, there are several benefits promoted by ART, such as reduction in mortality and the occurrence of opportunistic infections. Its effectiveness is associated with satisfactory adherence to treatment and can promote an increase in the expectation and quality of life of people with HIV/AIDS.[8]

It is worth mentioning that adherence to ART consists of the patient being responsible for the follow-up of his/her medication treatment, together with the multidisciplinary team, devising strategies so that the medication management is maintained in order to guarantee the maintenance of low levels of viral load.[9] A study carried out with 333 seropositive people identified that when the individual has some psychosocial disorder, he/she becomes more likely to not adhere to ART, compromising his/her quality of life, as the viral load will remain high. Poor adherence to ART increases substantially the risk of individual morbidity and mortality and transmission of the virus.[10]

Questions about the future and uncertainty call into question the decision to adhere to ART. In this sense, humanized care that includes guidance on the current health status and expected results can have a significant effect on decision-making in a positive way.[11] Periodically discuss the problems faced, both by the patient and the team, and enable the exchange of information experiences and dailyliving among those living with HIV/AIDS are simple measures that can favor the change of the current reality, improving the indicators of treatment adherence.[12]

In view of the above, it is necessary to ensure the empowerment and control of the person himself/herself in relation to his/her therapeutic scheme, in order to have an effective response to treatment.[6]

Therefore, due to the impact caused on the individual's quality of life and the consequent worsening of his/her health status, it is of great importance to carry out this study, since it will provide professionals involved in the care of HIV-positive patients, especially nurses, data that may be subsidies for the reorganization/ implementation of actions and/or conduct aimed at improving assistance to this population.

In this perspective, the research emerged from the following questions: do people with HIV/AIDS manifest mental suffering, hopelessness, and adherence to antiretroviral therapy? Are hopelessness, mental suffering, education, and age associated with adherence to antiretroviral therapy?

The hypotheses of this study consist of: people living with HIV/AIDS have mental suffering and hopelessness; hopelessness and mental suffering are associated with adherence to antiretroviral therapy; education is associated with mental suffering, hopelessness and adherence to antiretroviral therapy for people with HIV/AIDS; mental suffering is associated with the hopelessness score; age is associated with mental suffering, hopelessness and adherence to antiretroviral therapy for people with HIV/AIDS.

OBJECTIVE

To analyze the association between mental suffering, hopelessness, age, and education when adhering to antiretroviral therapy of people with HIV/AIDS.

METHOD

Ethical Aspects

This research followed the ethical principles established in Resolution Nr. 466/2012 of the National Health Council, which concerns the Regulatory Guidelines and Norms for Research Involving Humans.[13] It was approved by the Ethics and Research Committee under the Opinion Report Nr. 2,269,394, CAAE 71135917.3.0000.5176.

Design, study location and period

Research characterized as cross-sectional and quantitative carried out in the outpatient clinic of a referral hospital for infectious diseases in northeastern Brazil from January to March of the year 2019.

Population or sample and inclusion and exclusion criteria

The calculation of the sample size of patients was based on the formula for finite populations, taking into account the 95% confidence level (Z∞=1.96), a sample error of 10% and a population size of 4,850 registered patients. and followed up at the referred outpatient clinic, resulting in a sample of 95 patients, who chose to end with a total of 100 patients, who were selected for convenience, consecutively.

The following inclusion criteria were used: age equal to or greater than 18 years, diagnosis of HIV/AIDS and being receiving outpatient care at the time of data collection. Mental impairment was evaluated by means of a previous description on the chart. All those who had impaired cognitive conditions that made it impossible to collect all items of the instruments were excluded because they might not understand and, consequently, would not answer the complete questionnaire.

Study protocol

Data collection took place in the form of an interview lasting 30 minutes, after explaining the objectives and ethical criteria to the study subjects. Instruments such as the sociodemographic and three validated scales were applied: Mental Suffering (SRQ20, Self-Reporting Questionnaire-20)[14], Beck's Hopelessness[15] and adherence to antiretroviral therapy through the "*Cuestionario para la Evaluación de la Adhesión al Tratamiento Antirretro viral en Personas com Infección por VIH y Sida*" (CEAT -HIV).[16]

The SRQ20 addresses mental disorders, composed of 20 questions that include physical and psycho-emotional symptoms, with the individual being able to answer yes or no, being given one point for each yes and zero for no. Mental distress score ≥7.[14] The Beck'sHopelessness Scale consists of 20 items with options for right or wrong answers, which can be classified as minimal hopelessness (zero to four); mild (5 to 8); moderate (9 to 13); severe (14 to 20).[15]

CEAT-VIH evaluates adherence to ART in people diagnosed with HIV/AIDS and consists of 20 questions with options for answers on a Likert-style scale with a range from five to one point for 17 items and the others with a variation of one to two points . Scores were used to classify adherence: >85 good adherence; 50-85 difficulty with treatment; and ≤49 non-adherence.[16]

The variables in the sociodemographic questionnaire included: gender, age, marital status, and education.

Statistical Analysis

Data analysis was performed with the aid of the Statistical Package for the Social Sciences (SPSS) - version 19.0. The sociodemographic data of the Mental Suffering, Hopelessness and CEAT-HIV scales were performed using descriptive statistics with absolute and relative frequency, mean, standard deviation of the mean, maximum and minimum. To ascertain the hypotheses of the study, a significance level (p) of 5% (0.05) was used.

The Kruskal Wallis test was used to test whether the classification of hopelessness influences adherence to antiretroviral therapy, whether education influences mental suffering, hopelessness, and adherence to antiretroviral therapy for people with HIV/AIDS.

The t Test was applied to test whether the mental suffering score influences the hopelessness score, as well as whether age influences the mental suffering, hopelessness, and adherence to antiretroviral therapy scores. To test whether mental suffering influences the classification of hopelessness in people living with HIV/AIDS, the chi-square test was applied. To check whether adherence to antiretroviral therapy is influenced by mental suffering, the Mann Whitney test was used.

RESULTS

The study subjects had a maximum age of 68 and a minimum age of 20 years, with an average of 23.5±10.3. As for gender, 64% were men and 42% women. It was observed that 45% were single, 40% married, 10% divorced and 5% widowed. With regard to education, 5% without education, 50% attended elementary school, 31% had incomplete high school, 10% completed high school and 4% incomplete higher education. In the response on sexual orientation, 70% said they were heterosexual. The mode of infection/contagion of HIV/AIDS was sexual in 90% of cases; syringe sharing by 5%; and 5% reported not knowing.

The average score of mental suffering was 10.5±2.8, hopelessness 9.3±4.5 and the difficulty with adherence to antiretroviral therapy 60±3.2. The information regarding the respective classifications is shown in Table 1.

Table 1 - Distribution of classifications of mental suffering, hopelessness, and adherence to antiretroviral therapy, people with HIV/AIDS (N = 100), Northeast, Brazil, 2019

Classification	N	%
Mental Suffering		
Present	58	58%
Absent	42	42%
Hopelessness		
Minimal	32	32%
Mild	48	48%
Moderate	12	12%
Severe	8	8%
Adherence to Antiretro viral Therapy		
Good adherence	32	32%
Difficulty with treatment	60	60%
Non-adherence	8	8

Table 2 shows the association between the study variables, testing the suggested hypotheses.

DISCUSSION

The average age group of people with HIV/AIDS obtained in the survey was 23 years old, corroborating other studies carried out in Brazil.[3]

In the period from 2007 to June 2019, a total of 300,496 cases of HIV/AIDS infection were reported, 69% of which were male.[2] These data confirm the 64% of prevalent male cases obtained during the survey. In other studies, there was also a male predominance among individuals diagnosed with HIV/AIDS.[17]

There was a prevalence of single individuals. This result was also identified in another study, in which 45% of those infected with HIV/AIDS were single.[18] Single people represented a significant number among those who were infected with HIV/AIDS, which may be associated with the fact that adolescents and young singlepeople are more likely to have multiple partners, which increases the chances of acquiring HIV infection.[19]

Most had completed elementary school, which converges with studies that describe the level of education as an indicator that correlates with socioeconomic variables. This is considered to be biased towards the high index of individuals with less education, contributing to a more epidemic in less favored societies.[18] However, in Brazil, 27.1% of the reported cases are of people with complete elementary education, thus validating the data presented in the results of this research.[3]

A review study conducted in China showed that people with HIV/AIDS are more likely to develop mental disorders such as depression and anxiety.[20] Depression and mental suffering are constant impacts on the lives of people with HIV/AIDS, and are mainly related to knowledge of the diagnosis: fear of social and family rejection, fear of death, stigmatization and loss of friendships.[21] Both corroborate the results obtained in the current study, which reveals that 58% had mental suffering.

Regarding the hopelessness of individuals diagnosed with HIV/AIDS, the study revealed that 60.7% have a minimum level of hopelessness, that is, hope prevailed in relation to the future. The positive result for HIV/AIDS can arouse negative feelings about the future in the person, in addition, the stigmas that permeate the disease can accentuate the feeling of hopelessness in these patients. For that, health professionals become relevant in this process, given that they can disseminate positive information about technological advances in the proposed treatments, as well as future expectations and, simultaneously, stimulate (self) care, aiming to strengthen positive feelings.[22]

Table 2 - Result of the significance of testing the hypotheses of the study, people with HIV / AIDS (N = 100), Northeast, Brazil, 2019

Hypotheses (h1)	Tests	P	Behavior
The hopelessness classification is associated with adherence to antiretroviral therapy	Kruskal Wallis	0.049	h1 isaccepted
Education is associated with mental suffering	Kruskal Wallis	0.879	h1 isrejected
Education is associated with hopelessness	Kruskal Wallis	0.708	h1 isrejected
Education is associated with adherence to antiretroviral therapy for people with HIV/AIDS	Kruskal Wallis	0.411	h1 isrejected
The mental suffering score is associated with the hopelessness score	t Teste	0.001	h1 isaccepted
The classification of mental suffering is associated with the classification of hopelessness of people with HIV/AIDS	Chi-Square	0.001	h1 isaccepted
Adherence to antiretroviral therapy is associated with mental suffering	MannWhitney	0.126	h1 isrejected
Age is associated with the mental suffering score	t Teste	0.001	h1 isaccepted
Age is associated with the hopelessness score	t Teste	0.001	h1 isaccepted
Age is associated with the score of adherences to antiretroviral therapy for people with HIV/AIDS	t Teste	0.001	h1 isaccepted

Another research resulted in a positive correlation between degree of adherence to ART and hope - individuals with good therapeutic adherence showed significantly more hope. In addition, depression and anxiety were negatively related to hope, while family school support was positively related.[23]

With regard to adherence to antiretroviral therapy, the difficulty with treatment prevailed in 60%. In a study in the city of *RibeirãoPreto* -SP, it was possible to identify that 75% participants had a good/strict degree of adherence.[24] This result is contradictory to that presented by interviewed individuals, which can be explained by variations in access to quality treatment, lifestyle and early diagnosis, since the studies were carried out in different regions of Brazil.

Given the hypothesis that the hopelessness classification is associated with adherence to antiretroviral therapy, it is clear that complete therapeutic adherence is difficult, given the number of drugs and pills prescribed, side effects and interactions between themselves or with other medications, in addition to food, alcohol and other drugs. At the same time, the fear of suffering, social exclusion and the lack of educational material also seem to influence adherence to ART.[25]

The mental suffering score is associated with the hopelessness score since HIV/AIDS infection is considered a traumatic and stressful experience that can negatively affect mental health status and potentially lead patients to a cycle of physical and mental decay.[26] Thus, the classification of mental suffering also influences the classification of the hopelessness of people with HIV/AIDS, as demonstrated in the research based on statistical significance.

Age is associated with scores of mental suffering, hopelessness and antiretroviral therapy for people with HIV/AIDS, due to several factors, such as fear of stigma and the possibility of revealing their serological condition through the use of such medications, satisfaction with life, working and income conditions, social support and confidentiality about the disease.[27]

Study limitations and contributions to Nursing, health or public policy

As it is a cross-sectional study, it was not possible to monitor the study participants at other times, in addition to the time of data collection. The evaluation was made only by self-report and there was no other measure of the reliability of the report, presenting as a limitation the recall bias.

The present study contributes to the knowledge about the existing influences regarding antiretroviral therapy and its impaired adherence. Such knowledge allows opportunities to be traced for Nursing professionals to establish care directed to people diagnosed with HIV/AIDS in order to improve the quality of life and promote comprehensive care.

CONCLUSION

The results revealed that hopelessness is associated with adherence to antiretroviral therapy; mental suffering is associated with the hopelessness score; age is associated with the score of mental suffering, hopelessness, and adherence to antiretroviral therapy.

This information becomes priceless for those who work directly with people diagnosed with HIV/AIDS, as they contribute strongly to establishing rescue and recovery actions for those who suffer from an impaired situation, but it also constitutes a stimulus to stay at work, since it demonstrates higher prevalence of positive variables, such as the absence of mental suffering and minimal hopelessness, showing the result of a multiprofessional team performed by trained professionals. It also demonstrates the benefits of technological advances and human resources that allow people diagnosed with HIV/AIDS to have good or regular health conditions.

The possibility of verifying the reasons for the difficulty in adhering to antiretroviral therapy is added, and this challenge is launched for future research, health professionals and public managers.

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