



Stress level among young people living with HIV undergoing treatment: a descriptive-exploratory study

Nível de estresse entre jovens vivendo com HIV em tratamento: estudo descritivoexploratório

Nivel de estrés en jóvenes con VIH en tratamiento: estudio descriptivo-exploratorio

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ABSTRACT

Objective: to determine the stress level of young people living with HIV undergoing treatment. **Method:** a descriptive and exploratory study with a quantitative approach, conducted with young people living with HIV undergoing treatment in the Specialized Care Service of a reference hospital for infectious-contagious diseases. Data collection occurred from forms composed of sociodemographic questions and the following stress assessment instrument: the Stress Symptoms Inventory. **Results:** it was identified that most of the young people living with HIV suffer from stress, of the psychological type in the resistance phase. **Discussion:** the fact of living with the serology and the antiretroviral therapy can be a predictor for the manifestation of stress. **Conclusion:** it is recommended to implement actions that go beyond the physical harms in order to prevent mental illness in the course of HIV treatment.

DESCRIPTORS: HIV; Young people; Therapy; Psychological stress; Antiretrovirals.

RESUMO

Objetivo: averiguar o nível de estresse dos jovens vivendo com HIV em tratamento. **Método:** estudo descritivo-exploratório, de abordagem quantitativa, realizado com jovens vivendo com HIV que recebem tratamento no Serviço de Assistência Especializada de um hospital de referência para doenças infectocontagiosas. A coleta de dados ocorreu a partir de formulários compostos por questões sociodemográficas e o instrumento de avaliação do estresse: O Inventário de Sintomas de *Stress.* **Resultados:** identificou-se que a maioria dos jovens vivendo com HIV possuem estresse, do tipo psicológico encontrando-se na fase de resistência. **Discussão:** o fato de conviver com a sorologia e a terapia antirretroviral pode ser um fator preditor para manifestação de estresse. **Conclusão:** recomenda-se a implementação de ações que ultrapassem os danos físicos a fim de prevenir o adoecimento mental no curso do tratamento do HIV.

DESCRITORES: HIV; Jovens; Terapêutica; Estresse psicológico. Antirretrovirais.

RESUMEN

Objetivo: conocer el nivel de estrés de los jóvenes que viven con VIH y están en tratamiento. **Método:** estudio descriptivo-exploratorio, con abordaje cuantitativo, realizado con jóvenes que viven con VIH y que reciben tratamiento en el Servicio de Atención Especializada de un hospital de referencia en enfermedades infectocontagiosas. La recolección de datos se realizó mediante formularios compuestos por preguntas sociodemográficas y el instrumento de evaluación del estrés: el Inventario de Síntomas de Estrés. **Resultados:** se identificó que la mayoría de los jóvenes que vive con VIH tiene estrés, de tipo psicológico, y se encuentra en fase de resistencia. **Discusión:** el hecho de convivir con serología y terapia antirretroviral puede ser un factor predictivo para la manifestación de estrés. **Conclusión:** se recomienda implementar acciones que vayan más allá del daño físico para prevenir enfermedades mentales en el curso del tratamiento del VIH.

DESCRIPTORES: VIH; Joven; Terapia; Estrés Psicológico; Antirretrovirales.

INTRODUCTION

Infection by the Human Immunodeficiency Virus (HIV) has been progressing on a large scale in all regions of the planet, since its discovery in 1981 in the United States. In Brazil, between 2007 and 2018, an increasing trend was observed in the number of new cases among young people, with the percentage of infection in this population accounting for 23.5% of the total in the period⁽¹⁾. Since the incidence of HIV in adolescents and young adults has been increasing, the prevalence of emotional, psychosocial and health harms in this age group must be taken into account.

The Ministry of Health (*Ministério da Saúde*, MS) delimits youth as people aged 15 (fifteen) to 24 (twenty-four) years old, a phase of differentiated experiences and new meanings, characterized by the specific experiences that must be considered, for influencing the growth and maturation of the population in question⁽²⁾.

During this period, human beings go through a major change, caused by the maturation of the brain areas responsible for decision-making. This is only complete around 25 years old. In this phase, young people present characteristics such as impulsiveness, adopting risk behaviors and becoming more sensitive and susceptible to the use of psychoactive drugs and even to unprotected relationships, both being directly linked to HIV infection⁽³⁾.

The chronicity of HIV associated with adherence to the antiretroviral therapy (ART) is a challenge to be faced in experiencing the infection, triggering significant changes in the young individual's routine. Aspects such as the inopportune schedule of the medications, which

deprives young people from their usual activities, adverse effects and concern with the illness, produce tension and, consequently, psychological distress⁽⁴⁾.

Associated with these changes, other obstacles begin to be present in the lives of young people living with HIV, namely: not mentioning the infection for fear of rejection; concern in getting involved in relationships and in enjoying love and sexual experiences; disorders in selfesteem, which becomes affected by the disease; and body changes, among others. Some of the changes are related to the exclusion process associated with prejudice, influencing depression, feelings of rebellion, anxiety and even suicidal thoughts^(4.5).

All the aforementioned factors can lead the young person living with HIV to suffer from stress in their everyday life. As a cause of the changes in normal neurophysiologic functioning in the face of positive or negative situations, stress is characterized as a psychosocial phenomenon. The prevalence of the disorder in the world context has become a reason for concern and highlighted in contemporary times, arousing interest of bodies and professionals in the area⁽⁶⁾.

Some aspects can trigger stress among seropositive people, namely: the external sources in which the diseases stand out, changes in society and in the community related to the person living with HIV (PLHIV), such as the very discovery of contamination by the virus, reactions to the ART and the changes that occur in their social environment; and the internal aspects that are associated with the emotional states translated into feelings of

exclusion, rebellion, anxiety, fear and distress⁽⁷⁾.

These aspects are also related to the chronicity of the disease, which requires changes of an emotional and psychological nature to deal with the symptoms, treatment and diseases associated with HIV, escalating to stress and with the possibility of directly compromising the care of the PLHIV required by the disease, thus increasing transmissibility and impairing quality of life⁽⁸⁻⁹⁾.

From this perspective, it is worth noting that the research studies directed at the young population affected by HIV identified during the development of this study address diagnostic, clinical, therapeutic and preventive aspects of the infection, although without considering the significant mental ailment in the management of the problem. When evidenced in the literature, mental ailments are reduced to the emotional problems arising from the stigma, prejudice and social exclusion resulting from the experiences of the affected individuals.

Thus, the level of multifactor stress in this population must be evaluated, stress being one the major causes of damage to the immune system⁽¹⁰⁾, with the possibility of influencing the onset of opportunistic diseases in the population in question. Thus, the intention is to seek better effectiveness in assistance through the early identification of the problem and the planning of interventions by the health professionals, aiming at the physical, psychological and biological well-being of the users undergoing HIV treatment.

Given the above, the following guiding question was defined: Is there a significant stress level among young people living with HIV undergoing treatment? To answer this question, the research aimed at determining the stress level of young people living with HIV undergoing treatment.

METHOD

This is a descriptive and exploratory study with a quantitative approach, conducted in the Specialized Care Service (*Serviço de Assistência Especializada*, SAE) of a reference hospital for infectious-contagious diseases in the city of João Pessoa, Paraíba.

The population consisted of 211 patients aged 15 to 24 years old with HIV/AIDS who were undergoing treatment in the Hospital Complex at the time when the research was conducted. Therefore, the sample was calculated by means of the following formula⁽¹¹⁾:

$$n_0 = \frac{1}{E_0^2} \quad n = \frac{N.n_0}{N + n_0}$$

The population size (N), tolerable sampling error (5%) and first approximation to the sample size (n₀) were considered, accounting for a universe of 137 patients. Therefore, the sample was for convenience, totaling 60 patients who met the following inclusion criteria: being registered in that hospital; having a confirmed diagnosis of HIV/AIDS; being 15 to 24 years old; and being treated in the aforementioned hospital during the data collection period. Those who lacked the necessary physical conditions for the application of the data collection instrument were excluded.

The data collection process took place in July and August 2018, using the interview technique with application of the form consisting of sociodemographic questions (age, gender, marital status, race/skin color, religion, family income, profession/occupation, and assessment schooling) and the stress instrument (Stress Symptoms Inventory - SSI), validated and standardized by Lipp and Guevara in 1994. Its intention is to identify the symptoms presented by young people over 15 years old and adults, evaluating these stress symptoms by accurately identifying in what stage they are (12).

Periodicity of the meetings was single. They were carried out during the day period, from Monday to Friday and before and after the regular appointments scheduled by the service, according to the participants' availability, and in a private room offered by the hospital to ensure their privacy.

The SSI phases are in accordance with Lipp's fourth-phase stress model, namely: alarm, near-exhaustion, resistance, and exhaustion⁽¹²⁾. In addition to that, the predominant symptom type can be observed, either physical or psychological. The application of the instrument lasts approximately 10 minutes and can be done individually. It consists of 53 items, of which 34 refer to the physical symptoms and 19, to the psychological symptoms. The first stage consists of 12 physical symptoms and 3 psychological symptoms felt in the past 24 hours. In the second stage, the symptoms experienced in the last week are addressed, 10 being physical and 5, psychological. And in the third stage, the symptoms presented in the last month are

addressed, encompassing 12 physical and 11 psychological symptoms. The near-exhaustion phase can be identified from the frequency base of the third condition items. The subjects are assessed with stress if they obtain at least one of the following scores: seven or more points in the first stage; four or more points in the second stage; and nine or more points in the third stage. Tables are used to evaluate the answers indicated on the form, transforming into percentages the data collected in a manner predefined by Lipp to identify the stress level⁽¹²⁾.

The data were typed and stored in a Microsoft Office Excel 2013 spreadsheet for later transfer to the Data Entry Table of the *Statistica* 11.0 software by *Statsoft*. The selected variables were analyzed using statistical treatment so as to meet the stipulated objectives, with presentation of absolute and relative numbers in tables.

Prior to the interview, the adolescents who were over 18 years old signed the Free and Informed Consent Form (FICF), while those who were under 18 years old signed the Assent Form and their parents or legal guardian signed the FICF.

The research followed the precepts of Resolution No. 466 of 2012 of the National Health Council⁽¹³⁾, obtaining approval from the Research Ethics Committee of the Nova Esperança Nursing School, through CEP protocol: 137/2018 and CAAE 92876318.7.0000.

RESULTS

Initially, the sociodemographic characteristics of the young people monitored in their

treatment by the reference hospital in the state selected for the interviews were investigated. According to Table 1, it was verified that most of the interviewees belonged to the age group between 20 and 24 years old (85%), and that they were male (85%), single (86.7%) and considered themselves as brownskinned (61.8%), with prevalence of the Catholic religion (36.7%). Most of the young

people interviewed had a family income between one and three minimum wages (70%), followed by less than one minimum wage (21.7%). In relation to their profession/occupation, the highest percentage were students (36.7%). Regarding the young individuals' schooling, 46.7% reported attending high school; and the majority reported not having children (91.7%).

Table 1 - Distribution of the frequencies related to the sociodemographic variables of the young individuals interviewed. João Pessoa, PB, Brazil, 2018 (N=60)

Age 15-19 years old 09 15.0 20-24 years old 51 85.0 Gender Male 52 85.0 Female 08 13.3 Others 01 1.7 Marital Status Single 52 86.7 Married 06 10.0 Others 02 3.3			
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Others 01 1.7 Marital Status Single 52 86.7 Married 06 10.0			
Single 52 86.7 Married 06 10.0			
Single 52 86.7 Married 06 10.0			
Married 06 10.0			
Others			
Others 02 3.3			
Skin color/Race			
White 08 13.3			
Black 11 18.3			
Brown 37 61.8			
Others 04 6.6			
Religion			
Catholic 22 36.7			
Evangelical 19 31.7			
Others 14 23.3			
None 05 8.3			
Family Income			
<1 minimum wage* 13 21.7			
1-3 minimum wages 42 70.0			
>4 minimum wages 5 8.3			
Profession-Occupation			
Unemployed 17 28.3			

VARIABLES	F	%
Student	22	36.7
Liberal professional	05	8.3
Others	16	26.7
	Schooling	
Elementary School	15	25.0
High School	28	46.7
Higher Education	17	28.3

^{*}Minimum wage at the time in Brazil = R\$ 954.00.

Source: Prepared by the authors, 2018.

In relation to the time knowing their seropositivity for HIV and to the initiation period of the medications as presented in Table 2, prevalence of discovering the diagnosis in a period higher than 1 to 5 years

was verified (46.7%). As for the time of treatment initiation, there was prevalence of those that did so in a period over 1 to 5 years (41.7%).

Table 2 - Distribution of the frequencies corresponding to the variables related to the time of diagnosis and treatment. João Pessoa, PB, Brazil, 2018 (N=60)

VARIABLES	F	%	
Time of Diagnosis			
Up to 6 months	12	20.0	
>6 months – 1 year	13	21.7	
>1 year – 5 years	28	46.7	
>5 years	07	11.6	
Time of Treatment			
Up to 6 months	16	26.7	
>6 months – 1 year	12	20.0	
>1 year - 5 years	25	41.7	
>5 years	07	11.6	

Source: Prepared by the authors, 2018.

According to the data presented in Table 3, it was possible to identify that most of the young individuals (60%) reported symptoms related

to the presence of stress, according to the SSI instrument.

Table 3 - Distribution of the frequencies related to stress among the young individuals interviewed. João Pessoa, PB, Brazil, 2018 (N=60)

VARIABLES	F	%
Young people with stress	36	60.0

VARIABLES	F	%
Young people without stress	24	40.0

Source: Prepared by the authors, 2018.

Regarding the identification of stress, it was verified that 60% (n=36) of the interviewees presented stress symptoms, with the resistance phase standing out (69.5%). Simultaneously, from Table 4, it was also possible to identify the predominant type of

symptoms, where most of the participants reported the presence of psychological symptoms (75%), followed by physical symptoms (19.4%) and combined, that is, physical and psychological (5.6%).

Table 4 - Distribution of the frequencies of the young individuals identified with stress according to the phase and to the most prevalent symptoms. João Pessoa, PB, Brazil, 2018 (N=60)

VARIABLES	F	%		
Stress Phases				
Alarm	0	0.0		
Resistance	25	69.5		
Near-exhaustion	4	11.1		
Exhaustion	7	19.4		
Predominant Symptoms				
Physical	7	19.4		
Psychological	27	75.0		
Physical and psychological	2	5.6		

Source: Prepared by the authors, 2018.

DISCUSSION

In this study, the predominant age group among the interviewees was from 20 to 24 years old; this range complies with the epidemiological bulletin issued by the MS which points to the percentage of young people in this age group living with HIV from 2007 to 2018 accounting for up to 17.8% of the entire seropositive population, exceeding the values for the age group between 15 and 19 years old $(5.7\%)^{(1)}$.

Other prevalence values verified among the sociodemographic data were the following: most of the subjects under study were

male (85%) and single (86.7%). These characteristics can be confirmed from a research study conducted with people living with HIV, in which 91.7% and 61.5% of male and single individuals were recorded in the sample, respectively⁽⁷⁾.

Most of the young individuals living with HIV who participated in this study are brownskinned (61.8%), a percentage similar to the research⁽¹⁴⁾ developed in a municipality of the state of Bahia.

As for the religion variable, the Catholic (36.7%) one prevailed among the interviewees, followed by the

Evangelical (31.7%), corroborating the study⁽¹⁵⁾ conducted with people aged 18 years old or older and living with HIV, where the Catholic religion predominated (42.3%), followed by the Evangelical (36.5%), thus identifying that religiousness and spirituality are able to assist in the process of coping with the seropositive condition.

Although it is understood that being connected to a religion and maintaining spirituality exerts a positive influence on the improvement of quality of life, helping to cope with stress, stigma and the discriminatory factors related to seropositivity in young people, the association between religiousness and the influence of the variable on stress was not evaluated in the current research.

A study conducted with people living with HIV⁽¹⁶⁾ reinforces the predominance of dependence on incomes between 1 and 3 minimum wages; corroborating the findings of this study, it was found that 70% of the young individuals depend on such family income, showing low medium monthly family incomes.

As for the occupation of the young individuals interviewed, large part are only students (36.7%) or unemployed (28.3%). However, a research study conducted with seropositive young people contradicts such data when reporting that the minority (42.6%) are only students, with 66.7% committed to other occupational activities(14). Concerning the schooling level of the young people living with HIV, 46.7% are attending or have finished high school. From the study⁽¹⁷⁾, it was identified that seropositivity stood out in young people with more than 8 years of study, thus suggesting

failures in spreading AIDS/HIV prevention and control measures at the educational and governmental scopes.

When relating the problem of associating "being young" with HIV, it becomes extremely important to implement health actions for the target population, with a perspective on the prevention and control of HIV/AIDS. The actions must also evidence the value of family and school involvement in relation to the knowledge regarding the prevention means through safe sex practices. Thus, activities such as groups and conversations spaces among seropositive young people can stimulate coping and debate about each of the participants' experiences^(4,17).

The young individuals living with HIV who took part in this study were diagnosed and initiated their treatments in a period between 1 and 5 years (46.7% and 41.7%, respectively) from the collection date of this research. This data corroborates the information of the study⁽¹⁶⁾ conducted with people living with HIV that mostly presented a period above 12 months as time of diagnosis and treatment initiation. Then, the same authors identify that concerns about the ART respond positively to the quality of life index in the interviewees. Therefore, longer time of infection diagnosis and adherence to the treatment can be associated with better quality of life.

In relation to presence of stress symptoms among the seropositive young individuals undergoing treatment, it was identified that 60% presented symptoms; in other words, most of the population under study. Therefore, the young population in general goes through several changes, both biological and

psychological, in the search of their real identity, requiring differentiated and mature attitudes from them⁽³⁾.

Added to this, when hiding their serology to their peers, young people living with HIV can be affected by isolation, sadness and anguish that substitute the physical consequences⁽⁵⁾. Such situations of imbalance between the ability of the young individual and the demands of the social environment, also involving seropositivity, can lead them to the manifestation of stress symptoms, reducing their quality of life.

The fact of living with serology and ART can be a predictor for the manifestation of stress, since it changes the routine of the adolescents and young people living with HIV, with the possibility of causing side effects influencing treatment interruption^(4,18).

Most of the young individuals (69.5%) who presented stress symptoms were in the resistance phase. A study⁽¹⁸⁾ records that, obtaining family help, adolescents/young individuals needed to change their routine waking up at dawn to take medications, reason why young people living with HIV generally refuse to adhere to the treatment, with the need to adapt to new life routines, in addition to the limitations arising from the treatment, such as dealing with relationships and friendships that do not have the habit of taking medications and question the treatment of the young person living with HIV.

Thus, the young individual seeks to readapt and shape their body to carry out the daily activities, with risks of causing generalized wear out, associated with sensations of nausea, malaise, stomach pain, fear of falling ill and

discovery of the diagnosis by friends or partners⁽⁴⁾.

In addition to this, during their life phases, young people acquire skills for coping with the stigma caused by the disease, leading them to confront the feelings that lead to the development of stress and changes in their mental health⁽¹⁹⁾. Thus, they try to adapt to the new demands required by their situation, and reach the predominant stress phase: resistance.

Among the physical and psychological symptoms of the stress assessment instrument used, there were significant records of psychological symptoms (75%) of those young people who presented signs indicative of stress. The predominant symptom is characterized by low acceptance during the coexistence of the HIV diagnosis with high stress levels, culminating in anxietv and depression symptoms⁽²⁰⁾.

Corroborating this study, a national research study conducted with young people living with HIV indicates that the main psychological symptoms reported are irritability, depressive feelings and nervousness leading to stress, with the possibility of being associated with changes in family relationships and with a feeling of rebellion⁽⁴⁾. The manifestation of psychological symptoms can influence non-adherence to the ART, causing an increased viral response due to low immunity, leading to progression to AIDS.

Study limitations

The study limitations are related to the sample size, considering unfeasible the time needed to collect a larger number, since this is a clipping

from an undergraduate course completion paper.

CONCLUSION

The prevalence of stress symptoms among seropositive young people who are on ART is strongly associated with the psychological specificities inherent to the age group, in addition to their serological status. When present, these symptoms can drive the massive onset of biological and psychological diseases. Therefore, the study objective was achieved, and it can be concluded that most of the respondents are in the young adulthood phase, and presented male, students, symptoms, resistance being the most prevalent phase in which they were. The symptoms that predominated, between physical psychological, were of a psychological nature and it can be inferred that such findings are of concern for the population studied, since seropositivity requires extra care regarding the immunity level, as stress is a major factor for the reduction in the level of antibodies. It certainly needs to be mentioned that the study limitation was due to the difficulty accessing

the target population, given the long interval between each appointment scheduled.

The data indicate psychological distress in HIVpositive young people, motivating reflection in the professionals who provide assistance to this population in order to implement actions that go beyond the physical harms aiming to prevent mental illness in the course of the treatment. Thus, it is recommended that the health actions offered to seropositive young people go beyond the clinical dimension predominantly focused on the biological aspects to recognize psychiatric disorders, through active and sensitive listening, in addition to effective interventions minimize or reverse the mental illness condition in order to turn this young individual into a protagonist of their care, adherent to the treatment and with satisfactory immunological conditions to cope with HIV/AIDS. The importance that new studies be conducted addressing aspects related to the mental health of people living with HIV/AIDS to rethink specific actions and strategies in the care of physical and mental demands as a result of HIV infection and treatment is reiterated.

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