

Individual, social and program-related vulnerability in adults' adherence to antiretroviral treatment

Vulnerabilidade individual, social e programática na adesão ao tratamento antirretroviral em adultos

Vulnerabilidad individual, social y programática en la adherencia al tratamiento antirretroviral en adultos

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ABSTRACT

Objective: to examine how adherence to antiretroviral therapy among adults with HIV/Aids associated with dimensions of vulnerability. **Methods:** this quantitative study of 230 patients in a specialized service used questionnaires to assess adherence to treatment. The resulting data were submitted to inferential analysis. **Results:** adherence was good/adequate in 44.3% of patients and associated with elements of vulnerability, which could be individual: support to talk or vent about the health problem ($p = 0.002$), support for fun or leisure activities ($p = 0.000$), and for not taking medication due to a change in medical prescription ($p = 0.018$); social: sex ($p = 0.005$); education level ($p = 0.010$), family income ($p = 0.034$), and employment status ($p = 0.007$); or program-related: access to the service ($p = 0.005$), receiving information ($p = 0.039$), communication with professionals ($p = 0.024$), health education ($p = 0.013$), and not taking medication for not having them ($p = 0.039$). **Conclusion:** Adherence was classified as good or adequate, and pointed to elements of vulnerability that weaken or strengthen adherence. **Descriptors:** Acquired Immunodeficiency Syndrome; Antiretroviral Therapy, Highly Active; Medication Adherence; Health Vulnerability.

RESUMO

Objetivo: analisar a associação da adesão à terapia antirretroviral em adultos com HIV/Aids e as dimensões das vulnerabilidades. **Métodos:** estudo quantitativo, com 230 pacientes de serviço especializado, por meio de questionários de avaliação da adesão ao tratamento, com dados submetidos à análise estatística inferencial. **Resultados:** dos pacientes, 44,3% apresentaram boa/adequada adesão com elementos da vulnerabilidade individual: apoio para conversar/desabafar sobre o problema de saúde ($p=0,002$); apoio para se divertir ou fazer atividade de lazer ($p=0,000$); e deixar de tomar a medicação devido à alteração na prescrição médica ($p=0,018$); social: sexo ($p=0,005$); nível de instrução ($p=0,010$); renda familiar ($p=0,034$); e condição empregatícia ($p=0,007$); e programática: acesso ao serviço ($p=0,005$); recebimento de informações ($p=0,039$); comunicação com os profissionais ($p=0,024$); educação em saúde ($p=0,013$); e deixar de tomar a medicação por não tê-la ($p=0,039$). **Conclusão:** a adesão foi classificada como boa/adequada e apontam-se elementos de vulnerabilidades que fragilizam ou potencializam a adesão.

Descritores: Síndrome de Imunodeficiência Adquirida; Terapia Antirretroviral de Alta Atividade; Adesão à Medicação; Vulnerabilidade em Saúde.

RESUMEN

Objetivo: analizar la asociación de la adherencia a la terapia antirretroviral en adultos con VIH/SIDA y las dimensiones de las vulnerabilidades. **Métodos:** estudio cuantitativo, junto a 230 pacientes de servicios especializados, mediante cuestionarios para evaluar la adherencia al tratamiento, cuyos datos se sometieron al análisis estadístico inferencial. **Resultados:** el 44,3% de los pacientes tuvo buena / adecuada adherencia con elementos de vulnerabilidad individual: apoyo para hablar o desahogarse sobre el problema de salud ($p = 0,002$); apoyo para divertirse o realizar actividades de ocio ($p = 0,000$) y no tomar medicación por cambio de prescripción médica ($p = 0,018$); social: sexo ($p = 0,005$); nivel educativo ($p = 0,010$); ingresos familiares ($p = 0,034$) y situación laboral ($p = 0,007$); y programática: acceso al servicio ($p = 0,005$); recibir información ($p = 0.039$); comunicación con profesionales ($p = 0,024$); educación en salud ($p = 0,013$) y no tomar medicamentos por no tenerlos ($p = 0,039$). **Conclusión:** La adherencia se clasificó como buena / adecuada y se señalan elementos de vulnerabilidades que debilitan o mejoran la adherencia.

Descriptor: Síndrome de Imunodeficiencia Adquirida; Terapia Antirretroviral Altamente Activa; Cumplimiento de la Medicación; Vulnerabilidad en Salud.

INTRODUCTION

In the context of HIV/AIDS, patient adherence to antiretroviral therapy is one of the greatest challenges. The concept of adherence to antiretroviral treatment (ART), as defined by the Ministry of Health of Brazil, refers to a continuous, flexible and multifactorial process which includes biopsychological, sociocultural and behavioral aspects. This must occur through shared decisions and co-participation between the patient, professionals and the social network¹.

In order to understand adherence, there is the concept of vulnerability which seeks to respond to the chance of exposure of people to HIV and to becoming ill with AIDS as a result of a set of individual, collective and contextual aspects. Such aspects cause greater susceptibility to infection and illness, and inseparably greater or lesser availability of resources of all kinds to protect themselves. Vulnerability analyses integrate three interdependent dimensions which involve aspects of the subjects' lives, making them more or less susceptible to HIV infection, illness or death from AIDS², namely the individual, programmatic and social dimensions.

The individual dimension assesses cognitive, behavioral and social aspects, and as such result in meaning to be operationalized in protection practices. In turn, the social encompasses structural aspects related to education, the media, social, economic and health policies and citizenship, gender, culture, and religion (among others); these aspects are related to the constitutive aspects of the other dimensions, determining or mediating them. The program consists of effective and democratic access to the social and institutional resources necessary to avoid exposure to diseases, in addition to the possibility of accessing means of protection^{2,3}.

In this study, adherence to antiretroviral treatment was analyzed from the perspective of the concept of vulnerability. It is also considered that people living with HIV/AIDS (PLWHA), in their historical, social and epidemiological contexts, are part of vulnerable groups or individuals, meaning that they are legally or politically weakened in the promotion, protection and/or guarantee of their citizenship rights⁴.

Given the above, there is the relevance of this study for the health area, especially for nurses from specialized services so that they can identify the vulnerabilities of PLWHA and their implications on the adherence degree to ART. Thus, this study aimed to analyze the association of adherence to antiretroviral therapy in adults living with HIV/AIDS and the vulnerability dimensions.

METHOD

This is a cross-sectional study with a quantitative approach, conducted in a Specialized Care Service for HIV/AIDS (SCS), located in a municipality in the interior of the state of Ceará, Brazil, which is responsible for treating and monitoring patients belonging to the 53 municipalities in three neighboring states: Ceará, Paraíba and Pernambuco. The SCS conducts routine consultations, exams and medication dispensing.

The study population was previously estimated at 560 patients with active medical records who had access to the unit in the last year. A confidence level of 95%, a margin of error of 5% and the proportion of favorable results of the variable population of 50% were established. The formula for calculating the sample size was used for linear correlation between quantitative variables for a finite population.

The final sample consisted of 230 patients. Sampling was done by convenience, which considered the following inclusion criteria: people aged 18 years or over in follow-up and/or treatment for HIV/AIDS, as well as being literate since the questionnaire was self-administered. It is noteworthy that 13 patients refused to participate in the study.

Data were obtained through interviews performed by the person responsible for the research protocol. Two semi-structured and self-administered questionnaires were used. The first questionnaire³ was adapted for the present study, consisting of the characterization of adults with HIV/AIDS and divided into three stages: a) Sociodemographic and economic: gender, skin color, education level, marital status, sexual orientation, income, employment, knowledge of the disease at work, and use of (illicit) drugs and alcoholic beverages; b) a Likert scale (1 to 5 points) was used regarding social support for the following items: maintenance of health monitoring in the service; access to the service; communication; participation in some group; support in healthcare, financial matters and service monitoring (medicines, exams, consultations, guidelines, information, health education, self-esteem, dialogue, treatment incentive and socialization); c) Clinical profile: time of HIV diagnosis, transmission mode, opportunistic infections, number of pills, changes in lifestyle, changes in medical prescription, lack of medication, duration of treatment, T-CD4 lymphocyte levels and plasma viral load³ values. It should be noted that these last data were complemented with those identified in the patients' medical records.

The other instrument used to capture the data was the "Cuestionario para la Evaluación de la Adhesión al Tratamiento Antiretroviral" (CEAT - VIH)⁵, Portuguese version, reliably tested and validated ($\alpha=0.64$) and composed of 20 questions about taking the medication⁵. The sum of all items has a minimum of 17 and a maximum of 89 points, which classifies the adherence degree as low/insufficient, good/adequate and strict adherence. Therefore, adherence to antiretroviral treatment was evaluated through sociodemographic, economic, social support and clinical profile of PLWHA correlated with the CEAT - VIH.

The data obtained were submitted to descriptive and inferential statistical analysis and processed using the Statistical Package for the Social Sciences® software program (version 22.0). The categorical and ordinal quantitative variables were described by the distribution of absolute and relative frequencies, and the scalar variables by the mean and coefficient of variation. Adherence levels were determined by summing the responses to the *CEAT – VIH^F* questionnaire, generating scores and percentiles at three levels: low/insufficient (gross score ≤ 74; percentile ≤ 49); good/adequate adherence (gross score between 75 and 79; 50-85 percentile); and strict (gross score ≥ 80; percentile ≥ 85).

The chi-squared test and Fisher’s exact test were used when appropriate in the bivariate analyses to analyze the association between adherence to antiretroviral treatment (outcome variable) and vulnerability in its three dimensions (predictor variables), for both 95% confidence levels and $p < 0.05$. The following vulnerability dimensions applied to the elements that predispose non-adherence to ART in PLWHA were used as an analytical category: individual, social and programmatic³.

After inviting patients waiting for a medical appointment, explanations were given about the research and scheduling. Data were collected individually from April to September 2016 at the institution in a private place. The research protocol was approved by the Ethics Committee for Research in Human Beings of the institution, and all participants signed the Informed Consent Form (ICF).

RESULTS

The majority of the 230 PLWHA on ART were male ($n=134$; 58.3%) and heterosexual ($n=109$; 73.1%), aged between 18 and 39 years ($n=109$; 50.3%) (minimum age 18, maximum 60), followed by people aged between 40 and 59 years ($n=42$; 46.7%), brown skin color ($n=152$; 66.1%), who lived with a spouse or partner ($n=93$; 41.3%), had incomplete elementary education ($n=72$; 31.3%), were unemployed ($n=154$; 67.2%), and with a family income of less than one minimum monthly salary ($n=110$; 47.8%), with the average of those who depended on income equal to 3.22 people. The distribution of participants for the adherence degree was as follows: good/adequate: 44.3%; low/insufficient: 42.2%; and strict: 13.5%, with an overall mean score of 76.51 for the first two adherence levels.

The elements of vulnerability which kept a relationship of interdependence and statistically significant association with adherence to ART are identified in Figure 1.

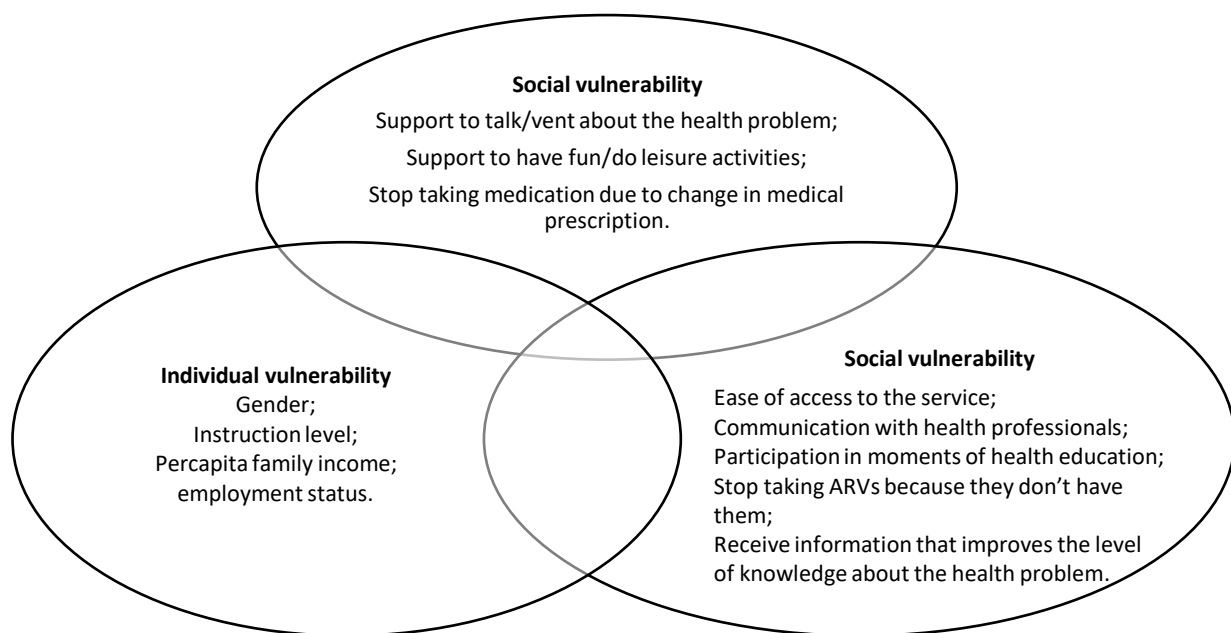


FIGURE 1: Dimensions of vulnerability and elements associated with adherence to antiretroviral treatment by people living with HIV/AIDS. Brazil, 2016.

Individual vulnerability was associated with the support of someone to talk or vent about the health problem ($p=0.002$); support from someone to have fun or do leisure activities ($p=0.000$); and to stop taking the medication due to some change in the medical prescription ($p=0.018$).

The elements which showed a statistically significant association with adherence in terms of social vulnerability were gender ($p=0.005$), with a higher level for the male population (47.8% good/adequate and 16.4% strict) when compared to the female population, which presented higher frequency in the low/insufficient level (51.0%); education level ($p=0.010$); per capita family income ($p=0.034$); and employment status ($p=0.007$).

There was a significant association regarding programmatic vulnerability: ease of access to the specialized care service ($p=0.005$); receiving information which improves the knowledge level about the health problem ($p=0.039$); communication with service professionals ($p=.024$); participation in health education moments ($p=0.013$); and to stop taking the medication because they do not have them (absence from the service) ($p=0.039$).

Table 1 identifies the people most involved in the process that ensure support for patients with HIV/AIDS, with an element of association with adherence to treatment.

TABLE 1: Study participants according to people who support antiretroviral treatment. Cariri, CE, Brazil, 2016.

Person who has given this kind of support to you	n (%)
Husband. partner or boyfriend	
No	120 (52.2)
Yes	110 (47.8)
Family member who lives with me	
No	110 (47.8)
Yes	120 (52.2)
Family member who does not live with me	
No	100 (43.5)
Yes	130 (56.6)
Friend	
No	144 (62.6)
Yes	86 (37.4)
Boss or co-worker	
No	228 (99.1)
Yes	2 (0.9)
Neighbor	
No	191 (83.0)
Yes	39 (17.0)
Service health professionals	
No	26 (11.3)
Yes	204 (88.7)

Health professionals (88.7%), family members who did not live with the study participants (56.5%) and family members who lived with the study participants (52.2%).

DISCUSSION

Elements of vulnerability associated with adherence to ART in adults with HIV/AIDS were identified. The main results of the study indicate that almost equal amounts had low/insufficient adherence and good/adequate adherence, being slightly higher in the latter.

The results obtained differ from a study carried out in Brasília which identified that 52.5% of the patients had good/adequate adherence to treatment, while 33.3% had low/insufficient adherence⁶. The advance in antiretroviral therapy is a reality, but the difficulty in accepting treatment by PLWHA and the side effects caused by the drugs make adherence a complex process, incorporating elements which must be taken into account in the work processes of health professionals, especially in specialized care services.

In this context, it is important to consider the constitutive elements of the three vulnerability domains in order to establish individual and collective strategies with a view to meeting the demands and health needs of patients.

From the perspective of individual vulnerability, the subjects in this study were provided affective support from family relationships and relationships outside the family context (health professionals) which had an impact on adherence to ART, especially in the form of conversation about issues related to health problems. A study carried out in São José dos Pinhais, Paraná, Brazil on social support and HIV observed significant differences regarding the availability and satisfaction with social support by patients, which provided greater adherence to treatment, both in the instrumental aspect related to care in managing and resolving practical situations of everyday life, as well as the emotional aspect which contributed to them feeling cared for and/or valued⁷.

An integrative review study on social support for older adults with HIV/AIDS showed a direct influence on quality of life and on coping with the disease, while its absence or insufficiency had repercussions on the existence of stigma in relation to the syndrome, isolation, care, and consequently on adherence to treatment⁸. Faced with the chronic condition of HIV/AIDS, it is considered that support is important for PLWHA to be able to strengthen and adhere to treatment in order to overcome obstacles. Thus, knowing the support network of these people can help to identify the social isolation they experience and intervene in this need.

In this study, it is possible to associate adherence to sharing leisure activities with other people, which can influence participants who had this access to achieve the best adherence levels to ART. A study carried out with patients assisted in outpatient consultations in Manaus, AM, Brazil identified a weak to moderate correlation with regard to the subjective well-being of PLWHA and adherence to treatment due to the difficulties and limitations to maintain the regular and continuous search for membership⁹. However, the highest adherence relationship occurred for those who have emotional support, as it facilitates coping with the illness process through perception or reaction to life situations⁷.

Considering that behavior and attitudes can influence treatment adherence, health services should encourage a practice that transcends interventions restricted to taking medication, but mental healthcare for these patients should be included so that they remain confident in life, and this must be especially ensured in specialized services.

Regarding social vulnerability, older adult men were more predisposed to adhere to ART, while the female population had a low/insufficient level, with a significant association when considering their education, income and employment status. This difference regarding the influence of gender and adherence to treatment is contradictory, as shown by studies in which there is no significant difference between men and women⁶.

However, a bibliographic study also identified an obstacle in adherence to ART related to the social context of the patients.¹⁰ In view of the above, the need for health professionals to consider the aspects which compose social vulnerability during individualized care is highlighted, since the context of life and work influences self-care, and consequently adherence.

The socioeconomic characteristics and adherence levels deserve to be highlighted, which showed better adherence for PLWHA with higher levels of education, income and who had a job; on the other hand, those with contrary conditions had a lower adherence level. In contrast, a study developed at the outpatient care service of the Specialized Reference Unit in Belém, Pará, Brazil pointed out that the profile of adherence to ART is not defined by socioeconomic data and patients should be encouraged to participate in adherence groups¹¹.

Nevertheless, most of the unemployed participants in this study had low/insufficient adherence. In fact, socioeconomic aspects seem to have weight in the vulnerability and non-adherence of PLWHA, but according to the above, one should consider promoting adherence so that adults can feel welcomed in the service and the relationship with their peers can provide an opportunity to exchange knowledge and overcome living with the syndrome.

Still with regard to the elements which compose the social dimension of vulnerability, differences were found between high and low educational levels and therapeutic adherence. Corroborating these findings, a study carried out in a city in the interior of São Paulo, Brazil identified that individuals aged between 40 and 59 years with a higher education level and longer diagnosis time showed good adherence¹². On the other hand, a study carried out in a health unit in Brasília did not identify a correlation between good adherence and different education levels⁶.

Therefore, it can be seen that the education level of PLWHA directly affects access to information, since this group generally has less argumentative power to seek their right to health and less economic power to have access to goods and services. In this sense, the health service needs to recognize such limitations and promote strategic actions which reach patients with less education, creating means and instruments that can contribute to their knowledge about HIV/AIDS.

Finally, regarding programmatic vulnerability, most PLWHA did not report difficulties with regard to access to the service, showing the highest adherence level. The expansion of access to consultations, the availability of health

professionals to clarify doubts and the shared care provided in a network can enhance adherence to treatment of young adults with HIV/AIDS¹³. It should also be noted that, even in the face of difficulties, a study carried out with young people between 15 and 24 years old in a municipality in the south of Brazil pointed out that they decided to follow the treatment in the search for a long life and normalized health¹⁴.

A study regarding the difficulty of access in Karwar (India) also showed a statistically significant association between the distance traveled to use ART services and the adherence level with patients who traveled more than 100 kilometers to get access to the health service; the study recognized the need for reception, additional support, and decentralization of services to nearby centers¹⁵. Therefore, the difficulty in accessing the service is one of the aspects which contribute to non-adherence. In turn, it is necessary to identify these demands and implement interventions to meet individual and collective health needs.

Communication between the patient and professionals proved to be a significant element in treatment adherence. A study with women living with HIV provided care by non-governmental organizations and a specialized care service at a university hospital in a city in Rio de Janeiro state showed that establishing active listening and good communication were effective in adhering to treatment¹⁶. Communication through messaging applications can also increase care for people with HIV, and is considered satisfactory¹⁷.

Thus, health professionals must make use of communication processes which enable identifying the needs and difficulties of PLWHA in experiencing the disease and treatment, seeking to overcome the difficulties encountered. It is also important to involve patients in this process, carrying out conscious and participatory work.

In this study, it was found that receiving information about their health problem improved the knowledge level and the adherence degree. This possibility has occurred in the service where the study was carried out, with developed health education activities with the objective of encouraging the conscious continuity of treatment. In fact, health education is a strategy that health services should use to promote adherence to ART, as a better adherence level has been identified when patients maintain communication with health professionals, receive support and information about the disease¹⁸.

Another relevant result of this study refers to the continuous availability of antiretrovirals in health services, which was associated with better adherence levels. In addition, one of the results with regard to programmatic vulnerability showed that patients stopped taking their medication when they were absent from the service. This data confirms the advance in the policy of universal and free distribution of antiretroviral medications in Brazil. This reality is quite different from what occurs in other countries, such as some on the African continent¹⁹, where PLWHA have difficulties in accessing medicines.

In summary, the elements regarding the individual dimension of vulnerability which were associated with adherence to treatment were support for sharing about the health problem, including leisure activities, and not taking medication due to changes in the medical prescription. Moreover, gender, education, family income per capita and employment status were identified regarding the elements of social vulnerability, while the following regarding the elements of programmatic vulnerability were verified: access to the specialized care service; receiving information at the health service that improves the knowledge level about the health problem; communication with service professionals; health education; and to stop taking the medication due to not having it (absence from the service).

Due to the diversity of elements that interfere with adherence to antiretroviral treatment, it is imperative that professionals responsible for providing care to PLWHA know how to recognize the elements that constitute a barrier and seek interventions which reverse the conditions that compromise adherence to treatment.

This study shows a limitation regarding the lack of information about the types of changes in the lifestyles of PLWHA due to treatment and whether such changes were an impediment to following the treatment, since such issues were not pointed out by the participants.

Adult patients with HIV/AIDS are vulnerable to adherence to ART treatment, as it involves multiple dimensions that demand monitoring, evaluation and approach to the support network of patients in the SCS, since this can reinforce the development of support strategies, disease control and better quality of life in this group. In this search, it is up to interdisciplinary care and that the service nurse promotes adherence to treatment by forming support groups which serve patients and family members.

CONCLUSION

This study showed that people living with HIV/AIDS in the Specialized Care Service had a good/adequate adherence level. The individual, social and programmatic dimensions of vulnerability showed elements which can be overcome through establishing public health policies, especially regarding health services in terms of improving access to services and requalifying the listening of health professionals in relation to the needs presented by PLWHA. The vulnerability elements identified reinforce the need to adopt nursing practices that promote interaction with adults with HIV.

Regarding the health services responsible for monitoring PLWHA, it is necessary to recognize the elements that weaken or enhance adherence and develop strategies which help to strengthen adherence to antiretroviral treatment, thus achieving better results with the therapy. In this study, it was evidenced that health professionals should promote comprehensive care, addressing and recognizing vulnerabilities in order to enable creating a bond and responding to the health needs of PLWHA.

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