Risk management in providing specialized care for people living with AIDS

Manejo de risco na gestão do cuidado especializado a pessoas vivendo com aids
Manejo del riesgo en la gestión del cuidado especializado a personas viviendo con sida

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ABSTRACT
Objective: Analyzing the provision of actions related to managing clinical risk in managing specialized care for people living with AIDS. Method: A cross-sectional study carried out in a reference outpatient clinic in Paraiba, with a sample of 150 adults with AIDS. Data were collected through primary and secondary sources using a structured questionnaire, analyzed using descriptive statistics, multiple correspondence analysis and logistic regression model to determine the association between "providing care" and "clinical risk." Results: Actions with satisfactory provision express a biological care focus; the dimensions that most contributed to a satisfactory assessment of care provision were "clinical and laboratory evaluations" and "prevention and self-care incentivization"; 45.3% of participants were categorized into high clinical risk, 34% into average clinical risk, and 20.7% into low clinical risk; a positive association between providing care and clinical risk was found. Conclusion: The need to use risk classification technologies to direct the planning of local care provision became evident considering its requirements, and thus qualifying the care provided in these areas.

DESCRIPTORS
Acquired Immunodeficiency Syndrome; Ambulatory Care; Chronic Disease; Risk Factors; Secondary Prevention; Public Health Nursing.

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INTRODUCTION

AIDS, due to its specific biological characteristics and its biopsychosocial implications inherent to living with the infection/illness/treatment, generates various health care demands whose resolutions require multidisciplinary care at different network services. These demands require care planning actions based on responsive care models to its chronicity(1-9).

Since the implementation of Antiretroviral therapy (ART), global evidence on variations in mortality patterns associated to its aggravation gave prominence to some comorbidities with the potential capability to generate losses in the survival of people undergoing treatment(3-5). Furthermore, although the underlying mechanisms are not precisely understood, the pathogenic potential of HIV to increase the risk of diseases not associated with immunosuppression is assumed(8). These aspects corroborate the relevance of the preventive approach of undesirable clinical outcomes in caring for infected people and undergoing specific treatment, so that there is proper management of infection in order to improve the health status, quality of life, and to reduce the mortality associated with HIV/AIDS(9).

In addition to the phenomena described, the targets established worldwide toward infection control over the next two decades(6) require efforts in the care management area, in addition to drug therapy. In the context of specialized care, actions aimed at identification and intervention of vulnerabilities are necessary; vulnerabilities to conditions which result in clinical instability and acute exacerbations triggered by viral pathogenesis, and also toxic effects of medications which have potential to compromise the clinical condition of the people undergoing treatment(9).

Thus, it is clear that on the list of actions for managing infection, the investigation of the severity of HIV/AIDS should not only consider the clinical complexity of the disease itself and its repercussion on the person’s quality of life, but also the risks of occurring events which can induce exacerbation(10). Such risks in this study are considered “clinical risks,” with the potential to influence the planning of care provision actions and the mobilization of resources and more effective technologies.

Care management logic(10) based on risk stratification enables organized measurement of actions and resources (clinical, human, financial) according to unique and differentiated patterns. Thus, for lower risk chronic conditions, supported self-care technologies would be employed with a focus on primary care services, while higher risk conditions would require a greater concentration of specialized care(10).

Among the programmatic factors associated with managing the risk of morbid events, the following can be highlighted: access to information, resources and technologies for the prevention/early diagnosis/treatment of opportunistic infections; access to tests and antiretroviral drugs/therapy (ART); addressing the biopsychosocial repercussions of diagnosis/illness/treatment; and strengthening social support networks aimed at improving the quality of life for people under supervision/undergoing treatment(2-13).

Therefore, this study aimed to analyze the provision of actions related to clinical risk management in providing specialized care for people living with AIDS.

The study is justified by the importance of the care provided in Specialized Healthcare Services (SHS) for identification and early intervention of the risk of unwanted clinical outcomes (clinical risk) with the potential to compromise the quality of life of people infected and undergoing ART treatment. This study is also anchored in the potential for classifying risk as an organizational element for providing care and as a guiding element for care management(3).

METHOD

A cross-sectional investigative study developed from July 2011 to July 2012 at a specialized outpatient facility for care of people living with HIV/AIDS (PLWHA), integrated into a reference unit in Paraíba for the treatment of infectious and parasitic diseases located in João Pessoa/Brazil. This unit has infrastructure for outpatient clinical care and inpatient beds and an intensive care unit.

The study population consisted of 1,260 people over the age of 18 years, living/residing in the state, and reported between 1980 and 2011 in the Notifiable Diseases Information System (SINAN). Using a sample calculation for finite populations, 5% significance level, sampling error (d) of 0.08, 95% confidence level, P equal to 0.50, expression n = Z^2 * p * q / d^2 (N – 1) + Z^2 * p * q and correction for a potential loss of 10%, the sample size was determined as being 150 users of the SHS.

Inclusion criteria considered for the sample was the use of ART for more than 6 months, and as exclusion criteria being under the age of 18, being pregnant or in a situation of liberty deprivation due to specificities of the clinical management of these populations and organization of the local care network.

In order to ensure that users of the service participated in the study, thus avoiding information bias, sampling accessibility was used with recruitment of participants occurring during routine consultations at the clinic. Data collection was initiated after clarification regarding the research and Clear and Informed Consent Forms were signed, primarily through structured interviews and subsequent consulting of patient records to obtain clinical data.

In order to achieve the objectives proposed by the study, the structured questionnaire included sociodemographic and clinical variables (T-CD4 positive/CD8 positive lymphocyte count and quantification of viral load), with the possibility of dichotomous or multiple answers, as well as variables for evaluating the provision of care, conceptually supported in the dimension of available services(12). For the latter, there were possibilities of Likert interval responses with values between 1 and 5, ascendingly representing the condition of agreement with the statements.

The instrument was initially used in a pilot study with 10 participants, submitted to content validation by a group of Operational Studies in HIV/AIDS of the Escola de Enfermagem de Ribeirão Preto, and reliability analysis using Cronbach alpha coefficient (α = 0.789), whose value allowed us to affirm its internal consistency. It was also found that the removal of each item composing the instrument did not strongly alter the value of this measure, displaying a balanced contribution of each variable in its structuring.

For classifying clinical risk, indicators of 1, 2 and 3 were initially assigned to lymphocyte values T-CD4+/CD8 (LT-CD4+/CD8), viral load (VL), quantity of opportunistic

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diseases, quantity of chronic diseases and quantity of clinical manifestations. The allocation of these indicators considered the respective laboratory parameters and clinical predictors of prognosis, response to ART, magnitude of major opportunistic conditions and clinical complications. Lower values (1) were assigned to positive parameters, while higher values (3) were assigned to negative parameters. Next, the categorized risk variable (sum of the five variable indicators) was calculated, with values ranging from 5 to 14, considering 5 = lower risk, 6 = medium risk, and high risk was > 6.

Data were analyzed using Statistica software 9.0 from STATSOFT, adopting 5% confidence levels for all procedures. Descriptive statistics presenting frequency were used to sociodemographically characterize the participants.

For analyzing care provision we considered the participant’s satisfaction for each variable that was expressed on a scale of 1 to 5, where average values of satisfaction were verified. These variables were then categorized into five dimensions according to content similarity. For the set of variables for each dimension, the sum score of all the answers from all the participants was determined, making a raw satisfaction score, which was transformed into percentage (scale from 0 to 100) using the equation: score % = \((score – minimum\ score) \times 100 / (maximum\ score – minimum\ score)\), and used to resolve possible biases arising from differences in the variable composition of each dimension. Next, average percentage of user satisfaction, their standard deviations and confidence intervals at 95% were calculated.

In order to explain the influence of the care provision dimensions (independent variables) on the determination of provision scores (dichotomized dependent variable), logistic regression was used, in which the general test for invalidation of the parameters presented desirable p-value (< 0.05) for its application and \(R^2\) Nagelkerke (0.98) very close to 1. The Hosmer-Lemeshow test (p-value > 0.05) accepted the hypothesis of adequacy of the data to the model, reaching 99.9% success in the classification matrix.

Correlation analysis was also used to explain the association between provision scores (independent variable) and categorized clinical risk (dependent variable), which presented greater explanatory power in dimension 1 (it presented 92.1% of total inertia, which was 100%).

This is part of a study approved in October 2010 by the Ethics Committee of the Universidade Federal da Paraíba – UFPB, protocol No. 612/10.

RESULTS

The socio-demographic profile of the participants showed a predominance of males (58.0%), aged 40–59 years (48.7%), brown color (58.7%), single (54.7%), heterosexual (68.5%), with primary education levels (53.3%), retired and pensioners (42.0%), living in their own home (62.0%).

Regarding the clinical risk classification, 45.3% (68) of the users were included in the category of high risk (6); 34% (68) in the average risk category (risk = 5); and 20.7% (31) in the low risk category (risk = 5).

For analysis of care provision related to risk management, the variables were categorized into five dimensions according to median values of the satisfaction scale (Table 1).

In the dimension Prevention and incentive to self-care, the socio-demographic profile of the participants showed a predominance of males (58.0%), aged 40–59 years (48.7%), brown color (58.7%), single (54.7%), heterosexual (68.5%), with primary education levels (53.3%), retired and pensioners (42.0%), living in their own home (62.0%).

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Table 1 – Dimensions of care provision according to the categorization of variables – Paraíba, Brazil, 2012.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Care Provision variable</th>
<th>Median</th>
<th>25 and 75 Quartile</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Guidance on family planning</td>
<td>1</td>
<td>[1-5]</td>
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<tr>
<td></td>
<td>Guidance on sexuality and condom use</td>
<td>5</td>
<td>[5-5]</td>
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<td></td>
<td>Guidance on food and nutrition</td>
<td>5</td>
<td>[3-5]</td>
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<td></td>
<td>Guidance on correct use of medicines</td>
<td>5</td>
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<td></td>
<td>Guidance on side effects of medicines</td>
<td>5</td>
<td>[3-5]</td>
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<tr>
<td>Prevention and incentive to self-care</td>
<td>Guidance on reducing the use of alcohol, tobacco and other drugs</td>
<td>5</td>
<td>[5-5]</td>
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<td></td>
<td>Guidance on criteria and government benefits application process</td>
<td>4</td>
<td>[1-5]</td>
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<tr>
<td></td>
<td>Guidance on vaccines</td>
<td>4</td>
<td>[1-5]</td>
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<tr>
<td></td>
<td>Vaccines</td>
<td>1</td>
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<td></td>
<td>Condoms</td>
<td>5</td>
<td>[5-5]</td>
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<tr>
<td>Clinical and laboratory evaluation</td>
<td>Routine medical consultation</td>
<td>5</td>
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<td></td>
<td>Consultation with the nursing staff</td>
<td>5</td>
<td>[4-5]</td>
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<td></td>
<td>Care due to complications</td>
<td>3</td>
<td>[2-5]</td>
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<td></td>
<td>Gynaecological care</td>
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<td></td>
<td>Dental care</td>
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<td>[1-5]</td>
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<td></td>
<td>Evaluation of hearing function</td>
<td>2</td>
<td>[2-2]</td>
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<td></td>
<td>Dermatological evaluation</td>
<td>2</td>
<td>[1-5]</td>
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<tr>
<td></td>
<td>Home visit</td>
<td>1</td>
<td>[1-1]</td>
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<tr>
<td></td>
<td>Evaluation and monitoring of the health status of partners and/or family members</td>
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<td>[1-5]</td>
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<tr>
<td></td>
<td>LT-CD4+ count</td>
<td>5</td>
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<td></td>
<td>Detection of VL</td>
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<td>Provision of other exams</td>
<td>5</td>
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<tr>
<td>Diagnosis of TB/HIV co-infection</td>
<td>X-ray*</td>
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<td></td>
<td>Sputum Test*</td>
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<td></td>
<td>Tuberculosis Skin Test (PPD)</td>
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<tr>
<td>Treatment</td>
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<td></td>
<td>Medications to avoid side effects of ART</td>
<td>1</td>
<td>[1-3]</td>
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<td></td>
<td>Medications to prevent opportunistic infections</td>
<td>1</td>
<td>[1-3]</td>
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<tr>
<td>Psychosocial support</td>
<td>Psychological support</td>
<td>5</td>
<td>[3-5]</td>
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<tr>
<td></td>
<td>Social assistance service</td>
<td>3</td>
<td>[2-5]</td>
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<tr>
<td></td>
<td>Support group/exchanging experiences/socializing</td>
<td>1</td>
<td>[1-1]</td>
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<tr>
<td></td>
<td>Information and incentive to participate in NGO/aids with operations in the state/municipality</td>
<td>1</td>
<td>[1-2]</td>
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* In the presence of respiratory symptoms, fever and weight loss.
satisfactory assessment (median = 5) can be highlighted with the provision of condoms and corresponding indicators for health promotion guidelines. On the other hand, the supply of vaccines and guidance on family planning (in situations where applicable) were negatively evaluated.

In the dimension Clinical and laboratory evaluation, provision was satisfactory for the variables of medical care, nursing care, gynaecological care and laboratory tests. The variables related to the provision of home visits, dermatological evaluation, evaluation of hearing function, dental care and care due to complications were assessed as regular or unsatisfactory.

All the variables in the dimension Diagnosis of TB/HIV co-infection were assessed as unsatisfactory (median = 1) or regular (median = 2), while in the Psychosocial support dimension only the provision of psychological support was assessed as satisfactory (median = 5).

In the dimension Treatment, unsatisfactory assessments were assigned to the provision of medication, both to avoid/reduce side effects of ART and to prevent opportunistic infections (median = 1). It is noteworthy that 16.0% (24) of users admitted feeling a need of using medications due to side effects, however they claimed that those were never offered.

Regarding the mean values of user satisfaction percentage according to the dimensions of care provision (Table 2), it was found that, none of the dimensions reached an average percentage satisfaction of 70% on a scale from 0 to 100, and that the psychosocial support dimension had the lowest average satisfaction.

The coefficients produced by logistic regression and used to express the contribution of the dimensions in determining the provision scores presented numerical values that, despite not having statistical significance, suggest that the dimensions that most contributed to satisfactory care provision were: clinical and laboratory evaluation (coefficient = 10.600) and prevention and incentive to self-care (coefficient = 8.919). On the other hand, the dimensions that most contributed to the unsatisfactory assessment of care provision were: treatment (coefficient = 2.528), psychosocial support (coefficient = 2.823) and diagnosis of TB/HIV co-infection (coefficient = 2.910).

In the association analysis and using dimension 1 as reference (92.1% of the total inertia), it was observed that due to proximity of where they are located, the levels of Unsatisfactory provision of care and High Risk are associated, as well as the levels of Satisfactory provision of care and Low Risk. Similarly, the levels of Average Provision of care and Average Risk are also associated. Complementarily, the Somers’ d association measure presents a negative value (-0.062), reinforcing the understanding that Provision of care and Risk are going in opposite directions.

Considering that 45.3% and 34% of participants were respectively classified as high and medium clinical risk, user satisfaction regarding the provision of actions in the dimension clinical and laboratory evaluations (54.29%) indicates the need to increase the service capacity beyond doctors, nurses and laboratory care.

The importance of monitoring immunologic status, as well as of medical and nursing consultations as strategic interventions for guiding subsequent conduct cannot be disregarded. It is known that clinical monitoring allows for identifying and the appropriate management of particular needs of the users; also, LT-CD4+/CD8 counts and VL enable detection of cases which are more prone to manifestations of disease symptoms, opportunistic infections and use a greater number of medications. However, the results in question justify the need for a multidisciplinary approach for the risk management of exacerbations and other events that may lead to death.

The classification of risk observed higher scores (scale ≥ 6) and their variable components indicate that these cases need more attention. It is known that the minimum skills required from SHS teams, weaknesses in the provision of home visits and evaluation/monitoring of the health status of partners and/or family members require investments...
in the extension of actions to family contexts. Service improvements include the development of a clinic that recognizes the individual and their family as a system, seeking the necessary social support in this core for better understanding of the person’s health status, and a consequent reduction in deleterious effects of the disease (15).

Another weakness of the service in this dimension involved the ability of responsiveness to already-present exacerbations, observed from regular satisfaction to care provision due to complications, an important gap to minimize adverse outcomes related to infection, associated diseases and the side effects of ART (16). It is noteworthy that opportunistic infections are recognized in international and national scenarios in different proportions as causes of hospitalization and death among people with HIV/AIDS, even after the introduction of ART (4,7).

Considering that the status of being HIV-infected generates some responsibilities to the individuals in caring for their own health, developing skills for self-protection is essential for changes to the life routine (involving sexual practice, diet and physical activity). Greater politicization and socialization of the population is also essential, in view of the physical hardship and psychosocial effects of having the infection and illness (17-18).

In this context, the dimension of prevention and incentive to self-care was well evaluated by the users (69.57%), signaling the provision of inputs and basic guidelines for the empowerment of users to adopt healthier lifestyle practices, preventing complications associated with immunosuppression and treatment. Satisfactory provision of condoms is an important input in the prevention of complications resulting from unprotected sexual contact, it encourages the exercise of sexuality in a responsible and safe manner, and prevents infection of seronegative partners, vertical transmission, and exposure to other sexually transmitted diseases (19-20).

Regarding healthcare professionals intervening in guiding users toward behavior changes in relation to their health and performing an educational role, they also stimulate a proactive approach on health management, being a fundamental behavior in the management of chronic conditions (15).

However, an asymmetry between guidelines on vaccines and the unsatisfactory provision of this important input for preventing opportunistic infections was observed, in view of the existence of special schemes that meet the specificities of this population regarding immunogenicity and the risks of using live attenuated agents (11).

It is worth mentioning that the dimensions that most contributed to the unsatisfactory assessment of the provision were: Treatment, Psychosocial support, and Diagnosis of TB/HIV co-infection. Although provision of ART medication was satisfactorily assessed, treatment complexity (extended time, number of doses and drugs, changes in lifestyle and side effects) contradicts the benefits in various proportions, creating adherence challenges to confront that require collaborative performance between users and medical staff in the micro-spaces of care provision. Thus, implementation of attention models directed to the person and which subsidize their co-responsibility in creating improvements for their health is necessary (11).

In this sense, not only is the provision of appropriate guidance essential, but also monitoring and controlling side effects in order to prevent failures in compliance which can lead to clinical complications. Therefore, the negative assessment of the provision of medication to prevent/reduce these effects (where a need in 16% of the participants was observed), is an important gap in the preventive approach of adherence barriers to ART. Nevertheless, the unsatisfactory assessment of the provision of drugs to prevent opportunistic diseases re-affirms the fragility of assistance in the treatment dimension, considering that the occurrence of these diseases impact morbidity and mortality, and generate damage to the quality of life of PLWHA (21).

AIDS chronicity and the diversity of its effects require professional assistance that enhances monitoring of psychosocial aspects in order for services to fully meet care demands (19). However, only the provision of psychological support was assessed positively in the dimension of psychosocial support. This fact indicates an important resource of care, as HIV status and treatment refer to psychological problems of varying severity that could impact the immune condition, adherence and quality of life (20).

It is known that living with an infection is characterized by coping with daily challenges that involve a set of constructed meanings and confronted in social life. It is also recognized that the participation of the family nucleus on the psychological well-being of HIV-positive individuals to enhance their self-esteem, self-confidence and self-image is fundamental to face adversities inherent in the diagnosis, living with the infection and the lifestyle changes necessary for effective treatment (21-24).

Hence the relevance of the support group and other collective activities, despite the existence of an ideal physical space for its realization in the unit, is contrary to the reality of other SHS (25), thus constituting a weakness of the service in the psychosocial support dimension.

Considering the historical role of civil society in confronting AIDS and its wide dissemination in defending the rights of people living with HIV, it is important to consider that non-governmental spaces have been gaining prominence for the social reintegration of these people and for the promotion of alternatives to reduce their vulnerability to illness (26).

Therefore, understanding the characteristics of social support and family interactions of users, as well as understanding and intervening in the availability of social apparatus with the potential to contribute to treatment (27) are actions that deserve to be valued by the service. This fragility in care provision can be understood as a remnant of the technical healthcare modalities of a curative nature which are supported by health care in the Brazilian system, collecting failures in the care of chronic conditions such as HIV/AIDS.

Considering that tuberculosis (TB) is the opportunistic disease with the greatest impact on morbidity and mortality due to AIDS in Brazil and in the world (27), priority actions for the prevention of infection among PLWHA include verifying the presence of suggestive symptoms at every doctor appointment and providing diagnostic tests (11).

In addition to being a resource for the diagnosis
of TB, bacilloscopy associated with sensitivity tests of *Mycobacterium tuberculosis* isolates enables knowledge of the sensitivity profile of the bacteria to the drugs used to treat infection, thereby assisting in the implementation of more effective treatments, considering that drug resistance is higher in this group. Tuberculosis Skin Test is important for diagnosing latent infection in PLWHA asymptomatic for TB, especially after immune reconstitution. X-rays, in addition to contributing to the differential diagnosis of other infections, can assist in excluding active TB when associated with a clinical and bacteriological examination; a necessary intervention prior to indicating treatment for latent infection to prevent induction of drug resistance.\(^{(13)}\)

The unsatisfactory assessment of the provision of these tests is a matter of concern in view of preventing complications and mortality of the service users, and it is an indication of weak performance in face of achieving global goals for AIDS control and related diseases.

The three provision dimensions with the lowest rates of satisfaction corroborate the observation that, despite advances in the treatment of HIV/AIDS, gaps in care are primarily focused on support to living with the infection and the psychosocial care needs, which in turn have repercussions on the ability of autonomy for self-care.\(^{(2,20)}\)

A study developed in southeastern Brazil signaled weaknesses in the provision of specialized service actions in meeting needs that were not related to clinical management and drug treatment, including those related to diagnosing and managing opportunistic infections, with TB being among them. Such a fact demonstrates that in different socioeconomic and programmatic realities, there are similar weaknesses in care management in the context of specialized services.

The measure of association between risk and provision suggests that in reality, service users with greater clinical risk might not be given priority for the provision of actions to meet their needs. This aspect deserves attention because when provision planning does not consider people whose health conditions require special attention, according to the stratification of their risk, efforts and resources are invested in unnecessary, misguided and ineffective interventions.\(^{(10)}\)

**CONCLUSION**

**RESUMO**

**Objetivo:** Analisar a oferta de ações relacionadas ao manejo de risco clínico na gestão do cuidado especializado a pessoas vivendo com aids. **Método:** Estudo transversal realizado em ambulatório de referência na Paraíba, com amostra de 150 adultos com aids. Os dados foram coletados por meio de fontes primárias e secundárias utilizando-se de formulário estruturado, e analisados através de estatística descritiva, análise de correspondência múltipla e modelo de regressão logística para averiguar a associação entre “oferta” e “risco clínico”. **Resultados:** As ações de oferta satisfatória expressam foco biologicista do cuidado; as dimensões que mais contribuíram para o julgamento satisfatório da oferta foram “avaliação clínica e laboratorial” e “prevenção e estimulo ao autocuidado”; 45,3% dos participantes foram categorizados em risco clínico alto, 34% em risco clínico médio, e 20,7% em risco clínico baixo; e verificou-se associação positiva entre oferta e risco clínico. **Conclusão:** Ficou evidente a necessidade da utilização de tecnologias de classificação de risco para direcionar o planejamento da oferta local, considerando-se as necessidades, e assim qualificar o cuidado produzido nestes espaços.

**DESCRITORES**

Síndrome de Imunodeficiência Adquirida; Assistência Ambulatorial; Doença Crônica; Fatores de Risco; Prevenção Secundária; Enfermagem em Saúde Pública.
Objetivo: Analizar la oferta de acciones relacionadas con el manejo de riesgo clínico en la gestión del cuidado especializado a personas viviendo con SIDA. Método: Estudio transversal realizado en ambulatorio de referencia en el Estado de Paraíba, con muestra de 150 adultos con SIDA. Los datos fueron recolectados por medio de fuentes primarias y secundarias utilizando formulario estructurado y analizados mediante estadística descriptiva, análisis de correspondencia múltiple y modelo de regresión logística para averiguar la asociación entre “oferta” y “riesgo clínico”. Resultados: Las acciones de oferta satisfactoria expresan enfoque biologicista del cuidado; las dimensiones que más contribuyeron al juicio satisfactorio de la oferta fueron “evaluación clínica y de laboratorio” y “prevención y estímulo al autocuidado”; el 45,3% de los participantes fueron categorizados en riesgo clínico alto, el 34% en riesgo clínico medio y el 20,7% en riesgo clínico bajo; y se verificó asociación positiva entre oferta y riesgo clínico. Conclusión: Resultó evidente la necesidad de la utilización de tecnologías de clasificación de riesgo para dirigir la planificación de la oferta local, considerándose las necesidades, y así calificar el cuidado producido en esos espacios.

REFERENCIAS


