Revista
Brasileira
de Enfermagem
REBEn

SUPPLEMENTARY EDITION 2
PROTECTION MEASURES FOR VULNERABLE POPULATIONS

ORIGINAL ARTICLE

Coping with the health condition from the perspective of people with HIV who abandoned treatment

Enfrentamento da condição de saúde na perspectiva de pessoas com HIV que abandonaram o tratamento

El enfrentamiento de la condición de salud en la perspectiva de las personas con VIH que abandonaron el tratamiento

Juliete Bispo dos Santos Mandu[I]
ORCID: 0000-0002-6883-1391

Elen Ferraz Teston[I]
ORCID: 0000-0001-6835-0574

Gleice Kelli Santana de Andrade[I]
ORCID: 0000-0003-3493-9190

Sonia Silva Marcon[II]
ORCID: 0000-0002-6607-362X

[I]*Universidade Federal do Mato Grosso do Sul. Campo Grande, Mato Grosso do Sul, Brazil.*
[II]*Universidade Estadual de Maringá. Maringá, Paraná, Brazil.*

How to cite this article:
Mandu JBS, Teston EF, Andrade GKS, Marcon SS. Coping with the health condition from the perspective of people with HIV who abandoned treatment. Rev Bras Enferm. 2022;75(Suppl 2):e20210958. https://doi.org/10.1590/0034-7167-2021-0958

Corresponding author:
Juliete Bispo dos Santos Mandu
E-mail: juliete-bispo@hotmail.com

EDITOR IN CHIEF: Antonio José de Almeida Filho
ASSOCIATE EDITOR: Priscilla Valladares Broca

Submission: 01-05-2022 **Approval:** 07-01-2022

ABSTRACT

Objectives: to understand how people living with HIV who have abandoned treatment face their health condition. **Methods:** a qualitative study, based on the Chronic Care Model theoretical precepts. Data were collected between April and August 2021, through interviews with 24 people registered in a specialized service in the Brazilian Midwest. **Results:** coping with the health condition included good and bad moments and is influenced by individual behaviors and the way in which the network was organized. Treatment abandonment was motivated by the absence of signs and symptoms, the way care is provided and medication side effects. **Final Considerations:** care actions focusing on behavior change and maintenance become necessary in order to favor continuity of treatment. Furthermore, the gaps identified in the way health services are organized are subject to intervention.

Descriptors: HIV; Acquired Immunodeficiency Syndrome; Therapeutics; Chronic Care; Continuity of Patient Care.

RESUMO

Objetivos: compreender como pessoas que vivem com o HIV e que abandonaram o tratamento enfrentam sua condição de saúde. **Métodos:** estudo qualitativo, fundamentado nos preceitos teóricos do Modelo de Atenção às Condições Crônicas. Os dados foram coletados entre abril e agosto de 2021, mediante entrevistas com 24 pessoas cadastradas em um serviço especializado no Centro-Oeste brasileiro. **Resultados:** o enfrentamento da condição de saúde incluiu momentos bons e ruins e é influenciado por comportamentos individuais e pelo modo com que a rede se organizava. O abandono do tratamento foi motivado pela ausência de sinais e sintomas, pelo modo como o cuidado é ofertado e pelos efeitos colaterais do medicamento. **Considerações Finais:** tornam-se necessárias ações de cuidado com enfoque na mudança de comportamento e manutenção com vistas a favorecer a continuidade do tratamento. Ademais, as lacunas identificadas no modo como os serviços de saúde se organizam são passíveis de intervenção.

Descritores: HIV; Síndrome de Imunodeficiência Adquirida; Tratamento; Doença Crônica; Continuidade da Assistência ao Paciente.

RESUMEN

Objetivos: comprender cómo las personas que viven con el VIH y que abandonaron el tratamiento enfrentan su condición de salud. **Métodos:** estudio cualitativo, basado en los preceptos teóricos del Modelo de Atención a las Condiciones Crónicas. Los datos fueron recolectados entre abril y agosto de 2021, a través de entrevistas con 24 personas registradas en un servicio especializado en el Medio Oeste brasileño. **Resultados:** el enfrentamiento de la condición de salud incluyó buenos y malos momentos y está influenciado por los comportamientos individuales y la forma en que se organizó la red. El abandono del tratamiento fue motivado por la ausencia de signos y síntomas, la forma de atención y los efectos secundarios de la medicación. **Consideraciones Finales:** se hacen necesarias acciones asistenciales centradas en el cambio y mantenimiento de la conducta para favorecer la continuidad del tratamiento. Además, las brechas identificadas en la forma en que se organizan los servicios de salud son objeto de intervención.

Descriptores: VIH; Síndrome de Inmunodeficiencia Adquirida; Terapéutica; Enfermedad Crónica; Continuidad de la Atención al Paciente.

ONLINE VERSION ISSN: 1984-0446

INTRODUCTION

Although living with the HIV virus or even the AIDS disease no longer represents a death sentence, as in the early 1990s, but rather a chronic condition that can be kept under control, its confrontation is still a challenge for health services. In Brazil, in 2019, there were more than 38 million people living with HIV (PLHIV)(1). Between 2007 and 2021, 381,793 cases of virus infection were reported, with an incidence of 32,701 in 2020, with a higher frequency of cases in the Southeast region (43.3%) and a lower incidence in the Midwest region (7.7%)(2).

Considering this epidemiological scenario, over the years, some strategies aimed at the treatment/monitoring of PLHIV have been implemented in the country that contributed to the improvement of clinical results and increased survival of this population group(3). Moreover, with the advent of antiretroviral therapy (ART), there were numerous benefits to the quality of life of these people and their link to health services(4). However, with the increase in life expectancy, new care challenges have emerged, such as the management of adverse events of ART in the long term, health complications of people who age with the disease, maintenance of ethical principles and the right to health, in addition to attending to social and economic factors, which can influence living with the disease and care actions. These challenges emphasize that care for these people cannot be restricted to dispensing ART, needing to consider the numerous factors related to chronic conditions(5).

In this context, it is important to highlight the importance of comprehensive and continuous care actions in the different points of the Health Care Network (RAS), in order to favor the maintenance of PLHIV's health(6-7), which is congruent with the purposes of the Chronic Care Model (CCM). CCM considers the specificities of chronicity and the conditions of illness, the related and interrelated contexts in this process and also the person, their family, the social support and health care network, services, professionals, management and policies involved(8).

Although there are strategies to encourage compliance with ART and maintenance of follow-up, treatment abandonment, characterized by non-attendance to the service for three months to withdraw ART or non-return to appointments for a period longer than six months(9), is still a prevalent problem and requires coping actions(10).

A study carried out at the Specialized Care Service/Testing and Counseling Center, a reference in PLHIV care in the state of Amapá, Brazil, identified the existence of mental problems (depression), the lack of a social support network and the difficulty to go to the health service as the main causes of treatment abandonment(11). In turn, a study carried out in the countryside of the state of Minas Gerais, with PLHIV who attend a specialized service, pointed out that, with the COVID-19 pandemic, the daily lives of these people were greatly changed, especially in relation to psychological, social and biological aspects, which influenced treatment abandonment(12).

Faced with this, the question is: what aspects interfere in the way people with HIV face their health condition? Does the understanding that PLHIV have about the disease influence them in treatment abandonment? What other factors interfere with abandonment? It is believed that the results of this study may direct care actions for PLHIV, including psychosocial aspects in the approach used with them during follow-up, which may result in an improvement in their health conditions.

OBJECTIVES

To understand how people living with HIV who have abandoned treatment face their health condition.

METHODS

Ethical aspects

This study complied with the ethical precepts provided for in Resolution 466/2012 of the Brazilian National Health Council. All participants signed the Informed Consent Form, and, to preserve their anonymity, in the presentation of results, extracts from their speeches are identified with the words Man and Woman to designate the biological sex, followed by a first number indicating age and a second referring to the time of diagnosis (e.g., Male 23, 6 years of diagnosis).

Study design

This is a descriptive and exploratory study, of a qualitative nature, which used the CCM as a conceptual basis, which elucidates the need for productive interactions between users of health services and the health team that is proactive and prepared. This model includes some tools for the organization and operationalization of care, such as the use of risk stratification, the existence of a shared clinical information system and the implementation of actions that favor self-care based on care practice(8).

The COnsolidated criteria for REporting Qualitative research (COREQ)(13) were used to guide the description of the study results.

Study setting

The study was carried out in the outpatient clinic of a state reference hospital for HIV/AIDS, viral hepatitis and other infectious and parasitic diseases, which also acts as a back-up for the outpatient clinic and infectious disease ward of the University Hospital, in a capital of midwestern Brazil. At the time of data collection, the hospital had nine unconventional hospitalization beds (day hospitalization), which allows the treatment and daily assessment of clinically stable PLHIV.

The service operates from Monday to Friday, in the morning and afternoon, with an average of 60 appointments per week, with an average of 12 medical appointments with an infectious disease specialist per day. In addition to specialist doctors, nurses, nursing technicians, psychologists, social workers, pharmacists and volunteer academics in the health area (medicine and nursing) work in the service.

Inclusion and exclusion criteria

We included PLHIV over 18 years of age who dropped out of treatment. In turn, we excluded individuals deprived of their liberty and those who reported not being able to go to work.

The possible participants were located from a list generated by the Medication Logistic Control System (SICLOM) referring to

PLHIV in treatment abandonment. Initially, the main researcher performed a nominal search in the service's epidemiological surveillance system to identify if there was a death record for some of the names included in the list, then she consulted the electronic medical records of all the people who remained in the relationship, in order to collect their telephone contacts. Subsequently, up to three contact attempts were made on alternate days and times, in an attempt to increase the success rate.

Of the 290 individuals included in the treatment dropout list, there were 41 deaths, seven duplicate records (users were undergoing treatment at another service), one record of a negative HIV test, six children and two people who used ART as post-exposure prophylaxis. Of the 233 PLHIV who could participate in the study, it was not possible to contact 175 of them by telephone, due to non-answering the call (17) or incomplete registration/absence of telephone number (158).

During the telephone contact made by the main researcher, the condition of treatment abandonment was confirmed, and, if so, as a strategy to return users to the service, an attempt was made to schedule a nursing appointment, which was performed by the main researcher, with the support of a health service nurse. The invitation to participate in the research was only made after the end of the nursing appointment, when the objective of the study and the type of participation desired were explained.

Of the 58 contacts made, two reported having no interest in returning to treatment; four scheduled the appointment, but did not attend; 26 had already returned to treatment, but the information had not been updated in the system; and 26 attended the nursing appointment. Of these, two refused to participate in the study, but, like the others, resumed treatment. The number of participants, therefore, was defined by exhaustion, as it included all contacted people who agreed to participate in the study and also the achievement of the proposed objective.

Data collection and organization

Data were collected from April to August 2021, through individual interviews, audio-recorded after authorization, on the same day and place of nursing appointment. The interviews lasted an average of 25 minutes and were guided by the following guiding question: what motivated you to abandon treatment? A script was also used, consisting of questions to characterize the participants, prepared by the main researcher (age, skin color, marital status, education, income, occupation and municipality of residence), and some support questions that addressed experiences throughout the disease, understanding of disease, health care actions and factors that facilitated and made health care difficult.

Data analysis

The interviews were transcribed in full, preferably on the same day of their completion, and submitted to content analysis, thematic modality, following the three stages proposed(14). In the pre-analysis, a detailed and exhaustive reading of speeches was carried out, to list the relevant points in relation to the study objectives. In material exploration, coding was performed, a process by which the raw data were systematically transformed and aggregated in the following units: health care; support network; changes after diagnosis; discontinuity in treatment; reasons that led to abandonment. Finally, the codes were grouped according to their similarities and gave rise to three categories, which were discussed in the light of CCM.

RESULTS

The 24 PLHIV, 12 of whom were women, were aged between 23 and 63 years (average of 37.9 years), 18 of them residing in the state capital and six in municipalities in the countryside. Thirteen of them were brown, six were black, four were white and one was yellow. Only three had completed higher education, seven had completed elementary school at most, and the others had completed high school (14). Regarding marital status, eight had partners, 13 were single, two were widowed and one was divorced.

At the time of the interview, ten participants received some type of benefit from the government, such as a family allowance (two), emergency aid (two) and the Organic Law of Social Assistance (OLSA) (six). As for occupation, two were retired, two were housewives and the others performed various activities. Chart 1 shows the reasons for treatment abandonment.

Chart 1 - Reasons referred to by PLHIV for treatment abandonment, Campo Grande, Mato Grosso do Sul, Brazil, 2021

Identification	Reasons for treatment abandonment
Man 1	Side effects of medication; weight gain
Man 2	Difficulty in accessing the service (locomotion); difficulty in connecting with the health service
Woman 3	COVID-19 pandemic; difficulty in accessing the service (locomotion)
Man 4	COVID-19 pandemic; difficulty in accessing the service (locomotion)
Man 5	COVID-19 pandemic
Woman 6	She searched the Bible and felt she was healed
Woman 7	Depression and anxiety
Woman 8	Does not accept the diagnosis
Man 9	Laziness to go to the service and does not care about the diagnosis
Woman 10	Shame to go to the health service
Woman 11	COVID-19 pandemic
Man 12	COVID-19 pandemic
Man 13	Discouragement, change of medication and schedule
Woman 14	Medication side effects; does not accept diagnosis
Woman 15	Medication side effects
Man 16	COVID-19 pandemic; difficulty scheduling appointment
Woman 17	Difficulty in accessing health services (locomotion)
Man 18	Difficulty in accessing health services (locomotion)
Man 19	He reports that he had medications at home, for this reason he did not return to the health service
Woman 20	COVID-19 pandemic; discouragement at having to go to work alone
Woman 21	Difficulty in accessing health services (time incompatible with work)
Man 22	Medication side effects; discouragement after death of wife in 2000
Man 23	Difficulty accessing health service (time incompatible with work); COVID-19 pandemic
Woman 24	Medication side effects (trouble sleeping)

From the analysis of all interviews, two categories emerged, which will be described below:

Coping with illness: changes occur early on, but do not always last

Among the changes that occurred in the life context of PLHIV, the participants highlighted that, soon after the diagnosis, they adopted specific health care and healthy habits:

> *I changed my diet, you have to take the medicine at the right time, you have to be up to date with exams, appointments, everything, vaccine, you have to be up to date with everything.* (Man 5, 7 years of diagnosis)

> *I played ball, cycled, went out, cut down on drinking, another thing that I changed a lot was in relation to my life, my routine changed a lot in relation to taking more care of sleep and body, I was more concerned not to abuse. We get older* [...] *and with this disease, resistance drops.* (Man 22, 23 years of diagnosis)

However, reports show that these behaviors sometimes did not sustain themselves over time.

> *Today, I don't take care of myself at all, I'm just eating silly, drinking too much, my diet is very complicated these days, but I've already taken good care of myself.* [...] *at first, I cared a lot, when I was in the hospital and the doctor told me, I called my psychologist first, because I was already following up with her, then I told her everything that had happened and I always talked to her a lot, and today I stopped.* (Man 1, 5 years of diagnosis)

Implicitly, the interviewees revealed that they understand the disease as a chronic condition:

> *They* [service professionals] *treated me like any other disease, in the sense of needing treatment, medical follow-up, they asked me if I was taking the medication, they always had this care.* (Man 4, 6 years of diagnosis)

> *Here it is shown that yes, it is possible to have a normal life, a healthy life, even with a positive diagnosis.* (Woman 14, 2 years of diagnosis)

The reports included in this category show that the changes that occurred after diagnosis did not always remain, although participants showed that they understand that the chronic condition requires care over time.

Factors that influence coping with the disease

The reports in this category highlight the strategies and/or factors that helped the PLHIV under study to face the disease, such as the perception of reception, whether in the church or in the health service itself:

> *I was welcomed inside the church. My psychological treatment was more in the church than in the office itself. They* [church staff] *opened another tab to serve me and several other people, and a really cool project started.* (Man 2, 3 years of diagnosis)

> *I felt taken care of, they were always very calm, affectionate, careful to be talking about the subject and they never made me feel bad for saying something in that sense, so I feel a little more comfortable.* (Man 4, 6 years of diagnosis)

> *The way in which each person is treated here, I think that, as much as we make the mistake of abandoning treatment and coming back after a while, the way we are treated here remains the same, nothing changes.* (Woman 24, 3 years of diagnosis)

The existence of a pregnancy and the feeling of responsibility towards a child:

> *I wanted to disappear* [laughs]*, but I remembered that he* [son] *was still in the belly, I had to be stronger for him.* (Woman 15, 5 years of diagnosis)

And the fact that you can help or be an example to other people:

> *This exchange of helping and being helped is pretty cool, because that's what helped me too.* (Man 2, 3 years of diagnosis)

> *I have a friend who turned positive and he said, "my friend, I just had this reaction that I had today, because I know you and I know you can live with the virus".* (Man 19, 6 years of diagnosis)

In turn, the reports also show that some people experienced difficulties in maintaining activities that validate the role of people in society, especially work. In these cases, the possible confrontation was the withdrawal of these activities:

> *My daughter used to say, "Mom, we know it's not transmitted like that". I had nothing that would contaminate the food, no wounds, or anything that would transmit it, but I stopped doing it to sell, because I thought I was putting other people's lives at risk, maybe that's why I stopped working and ended up getting depressed.* (Woman 8, 5 years of diagnosis)

> *When a person lives with HIV, it is difficult for society to accept to work. Look, I didn't want to anymore, because it's a bad feeling when you look for a service and have to say that you have the virus, it's very bad.* (Woman 20, 3 years of diagnosis)

Therefore, the strategies adopted by the research participants can act as instruments to alleviate fears, anxieties, weaknesses and conflicts, in addition to constituting possibilities to favor coping with the disease.

Factors that influence treatment abandonment

Some reports show that the idea of well-being caused by the absence of signs and symptoms strongly influences discontinuity of treatment:

> *I wasn't taking any medicine, but I didn't have anything and I didn't even need to come. I was fine, I thought if I'm fine then it's fine.* (Man12, 4 years of diagnosis)

> *Ah, I abandoned those times ago, in fact, it was careless not to go, as I didn't feel anything, I watched until I could stand it, feeling calm* [laughs]. (Man 13, 8 years of diagnosis)

Likewise, they emphasize that the lack of "support" and encouragement from close people can also discourage continuity of treatment, as well as the breaking of the bond with health professionals, the difficulties in traveling to the specialized service and the side effects of ART:

> *What made me leave was this lack of having someone charge me. I know that my main interest is mine, because my health is mine, no one will stand by me until I die, but then, we miss someone to incentive me.* (Man 1, 5 years of diagnosis)

> *I was under treatment with a doctor and she moved out. After she moved out, I had a lot of difficulty continuing my treatment, she was already a friend, I already had confidence, she was already part of the family, she had that bond and trust, even because she spoke in a way that was not demanding and without accusing.* (Man 22, 23 years of diagnosis)

> *I abandoned it because of transport* [...] *I lived on the farm, so I had to go to town to sleep and wait for the car to come, but I had no place to stay.* (Woman 3, 8 years of diagnosis)

> *It's been three times that I stopped doing the treatment, I felt sick mainly because of the medication side effects. There was vomiting, weakness and lack of appetite. I lost weight, I felt very bad, then I dropped the treatment and went back to feeling better, then, as I had no symptoms, I felt good as if I had nothing.* (Woman 7, 17 years of diagnosis)

Two other aspects were pointed out as negative for continuity of treatment: the unpreparedness of the other points of the RAS, in addition to specialized service:

> *Another service I went to looked like they were ashamed of us. In the service, it seemed they didn't want to, they treated us as if we were anyone, any type of disease, and it's not.* (Woman 3, 8 years of diagnosis)

> *If you tell me to go to the ECU instead of coming here, because it's closer, I'll continue to come here, because if I'm going to do some follow-up there, I won't. If I have a problem, I'd rather come here, make an appointment and come back another day, but I won't go somewhere else.* (Man 5, 2 years of diagnosis)

And the difficulty of accessing the specialized service, due to the restriction in the opening hours or in its form of organization:

> *I think it would make it easier for people who live abroad to release the medication at once, because this business of coming every month to get medication, for those who live abroad, is complicated.* (Woman 3, 8 years of diagnosis)

> *I've already experienced a lot of embarrassment for having to wait and face a huge queue... they said, "it's past time". I arrived at 7:30 am, because I have my jobs and my personal things and they said, "ah, the appointment is already over, you have to come back tomorrow", "ah, there is no vacancy, everything is filled", and that's where you end up not going to the doctor, not getting your medication and not having treatment. This really encourages the patient to give up treatment, I went through this and it has happened that I give up the treatment there because I have these problems inside the hospital. If you don't make an appointment, you don't go to the doctor, if you don't go to the doctor or nurse, you don't take medication.* (Man 23, 13 years of diagnosis)

Finally, considering the context in which the data were collected, the fear of contamination triggered by the COVID-19 pandemic was also pointed out as a reason to abandon treatment:

> *I was afraid to come, because the hospital is full of COVID, these people dying, so I was afraid to come.* (Woman 10, 10 years of diagnosis)

The findings of this category highlight aspects to be considered in the planning of actions aimed at the care of PLHIV, with a view, including, to prevent ART abandonment.

DISCUSSION

Some research participants understand the need for continuous health care in relation to adopting a healthy diet, not drinking alcohol and the need to perform physical activity. However, over time, factors such as the feeling of well-being, absence of signs and symptoms, lack of a support network, breaking the link with the health service and difficulty in accessing treatment, favored treatment abandonment and health care non-maintenance.

Sometimes, soon after the diagnosis of a chronic condition, individuals tend to adopt changes in behavior that favor their own health care. In the case of PLHIV, for example, the will to live can be a motivating factor for behavior change and a re-signification of their own lives(15).

It should be noted that actions to promote the well-being and quality of life of people with a chronic condition involve more than drug treatment, requiring the implementation of behavioral changes in relation to daily habits, in order to promote self-care, one of the elements proposed by CCM. Thus, considering that self-care actions taken by people with a chronic condition can delay disease progression and improve long-term health outcomes(16), identifying behaviors and risk factors allows professionals to build a joint, comprehensive care/self-care plan that favors continuous monitoring(17).

Concerning this, actions, such as the establishment of bonds between professionals and service users, favor comprehensive and continuous care. The bond gives health professionals the opportunity to identify unique needs and direct care actions with a view to promoting behavior change and supporting maintenance over time(18). A study carried out in Paraná highlighted the importance of consolidating the bond between professionals and users and the reception, even after abandoning treatment(19), these aspects are considered determinant in the adhesion, retention and linking of PLHIV to the RAS services.

It was observed, in the results, that the abandonment of daily actions, such as work activities, is influenced by the fear of experiencing stigma and prejudice in the work environment. This result supports a study conducted in Brazil with adults living with HIV, which pointed out the occurrence of withdrawal from occupational functions after discovery of diagnosis due to prejudice and discrimination(20). In view of this, the recognition of these experiences is essential in chronic disease management, as they guide the establishment of interventions that consider social determinants in health promotion(16).

Although each individual has their particularities in relation to coping with a chronic condition, the search for support in religion was found to be an important strategy adopted in this process. This finding corroborates the results of a study carried out with 48 seropositive elderly people from Recife, Pernambuco, which ratified the contribution of religion and/or the search for support in religious institutions to strengthen psychological and emotional aspects, in addition to promoting greater acceptance in compliance with treatment(17).

Other strategies can help to minimize the difficulties that permeate the chronicity of the disease, including the understanding that HIV is a treatable disease and not a death sentence(21) and the tightening of bonds and friendship between PLHIV created from the exchange of experiences in relation to the experience of the disease(22). These aspects act as strategies that minimize fears, anxieties, weaknesses and conflicts and, consequently, can positively impact treatment compliance.

It should be noted that people living with a chronic condition may not recognize the need to comply with drug treatment continuously, due to the absence of signs and symptoms(23), as identified in relation to some participants in this study. In view of this, it is asserted that the monitoring of PLHIV needs to be permeated by strategic actions that favor understanding of the possible repercussions resulting from the lack of adequate treatment.

Another reason for abandoning treatment highlighted by the participants was the absence of a support network. A literature review study points out that PLHIV who have a consolidated support network are more confident, persevering, comply better with treatment and accept the diagnosis more easily. However, when this network is weakened, failures occur in the therapeutic process, there is treatment abandonment, decline in physical and mental health conditions, sometimes responsible for increased viral replication and the emergence of opportunistic diseases(24). In this sense, the importance of identifying and mapping this network during the nursing appointment is highlighted, in order to include it in the planning and implementation of strategic care actions.

It was observed that the difficulty of using other services that make up the RAS, due to the way they are approached, which includes the lack of reception, was also mentioned as a factor that interferes with treatment maintenance. However, restriction of care to specialized care, in addition to overloading these services, also limits care. It is noteworthy that this chronic condition demands comprehensive and unique care that needs to be provided at different points in the RAS.

The decentralization of care to other points in the network involves, in addition to diagnosis, actions aimed at longitudinal and comprehensive care in the monitoring of PLHIV, providing an opportunity for services to respond to the growing demands of this population(25). However, a study carried out in Recife pointed out that, because it is a recent process for Primary Health Care (PHC), the decentralization of care for this portion of the population generates insecurity, which sometimes limits the work process for carrying out the rapid test(26). Thus, there is an urgent need to stimulate discussions between the different members of care team and managers, to strengthen the strategic actions of decentralization of care and circumvent flaws that can be identified in this process.

In this sense, a study carried out with professionals from three Family Health Strategy teams in Porto Alegre, Rio Grande do Sul, highlighted the potential that the decentralization process can bring, among which: greater sensitivity of PHC teams in relation to epidemiological data; expansion of access to monitoring the health and illness condition of these people; work logic guided by the principles of the Unified Health System (SUS - *Sistema Único de Saúde*) and family health; and expanding community participation(27). Thus, although permeated by some gaps, the process of decentralizing care to PLHIV constitutes an opportunity to expand the reception and linking of these individuals to health services, which is essential considering the difficulties that people face in maintaining behavioral changes in the long term(28). Faced with this, it is necessary to rethink the care practices offered to PLHIV at different points in the RAS, as the need to change behavior is essential in any chronic condition. Therefore, it is necessary to invest in light technologies that favor the strengthening of relationships between health teams and users.

The difficulties related to the flow of care in the RAS mentioned by the participants also corroborate the result of a study carried out in Fortaleza, Ceará, which found that the difficulty of access is a discouraging factor associated with discontinuity of treatment(29). However, it is necessary for individuals to recognize that access to the health service involves, in addition to taking the medication and carrying out a medical appointment, the provision of continuous monitoring actions.

It is unquestionable that compliance with ART is a fundamental factor in the total suppression of viral replication and in quality of life promotion, but there are still obstacles related to side effects. In this sense, In order to minimize these impacts, research carried out on the coast of Kenya, with 49 adults and young people living with HIV, pointed out that innovative treatment models, such as injectable ART, make it possible to reduce side effects and, consequently, treatment abandonment(30).

Still related to the care flow, it should be noted that the use of tools proposed by the CCM, such as risk stratification, assists in the identification of specificities and demands(31), which may be a possibility to make pre-established flows more flexible, since it organizes the care offer from risk strata. Its use by PHC professionals in the follow-up of other chronic conditions, such as hypertension, favored the development of comprehensive and individualized care(31).

Although there are no validated criteria for risk stratification of PLHIV in the literature, a study carried out in the state of Paraíba presents suggestions that can be used for clinical risk classification in PLHIV, such as detection of viral load, presence of opportunistic diseases, chronic diseases and clinical manifestations(32).

Finally, it is important to consider that public health emergency situations, such as the pandemic caused by the coronavirus, constitute a factor that limits access to health services. With regard to people with chronic conditions, assistance was interrupted, because professionals had to restructure the service dynamics, considering the transmission barrier of the COVID-19 virus and the reduction of risks to the population(33). Thus, although the scenario is one of exceptional situations, the importance of an attentive look of health teams for the early creation of new mechanisms that favor maintenance of care for PLHIV is highlighted, in order to prevent treatment abandonment and the emergence of future complications.

Study limitations

A limitation of this study is the impossibility of contacting all users identified as having abandoned treatment, due to outdated data recording and lack of integration between the specialized service and epidemiological surveillance systems. Likewise, the approach of people who voluntarily returned to the service could contribute to a better elucidation of the phenomenon under study.

Contributions to nursing and health

The identification of weaknesses that can influence treatment compliance and maintenance brings contributions to nursing and the health team, as it favors reflection on the way in which the network is organized, in particular, on the care decentralization process and the tools used in practice to stratify, recognize, welcome, link and retain PLHIV to health services, contributing to comprehensive and continuous care.

Furthermore, the results show that carrying out an active search for PLHIV who abandoned treatment, by telephone contact, for instance, constitutes a soft technology that can be adopted in the routine of services, being an effective strategy in the reduction of cases of treatment abandonment. To this end, it is essential to keep registration data updated, as well as the registration of several possible contacts.

FINAL CONSIDERATIONS

Coping with the health condition by PLHIV who abandoned treatment included good and bad times, and is influenced by individual behaviors and the way health services are organized.

Understand how PLHIV who abandoned treatment face their health condition, enabling the identification of care gaps that can influence compliance, attachment and retention of these people to treatment and care actions. It is necessary, during the planning of actions, to approach users regarding the importance of lasting behavior change, especially as it is a chronic condition. Moreover, after identifying the factors that help to address this chronicity, these factors can be used as potentiators of care actions.

FUNDING

The present work was carried out with the support of the Coordination for the Improvement of Higher Education Personnel - Brazil (CAPES - *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior*) - Financing Code 001 and the *Universidade Federal do Mato Grosso do Sul* (UFMS).

REFERENCES

1. Organização Mundial da Saúde(OMS). Updated recommendations on HIV prevention, infant diagnosis, antiretroviral initiation and monitoring [Internet]. WHO; 2021[cited 2021 Oct 31]. Available from: https://www.who.int/publications/i/item/9789240022232
2. Ministério da Saúde (BR). Departamento de Vigilância Prevenção e Controle das Infecções Sexualmente Transmissíveis do HIV/Aids e das Hepatites Virais. Boletim Epidemiológico HIV/Aids2021. HIV Aids Bol Epidemiológico. 2021; 72p.
3. Clutter, DS, Jordan MR, Bertagnolio S,Shafer RW. HIV-1 Drug Resistance and Resistance Testing. InfectGenet Evol. 2016;46(1):292–307. https://doi.org/10.1016/j.meegid.2016.08.031
4. Pimentel GS, Ceccato MGB, Costa JO, Mendes JC, Bonolo PF, Silveira MR. Quality of life in individuals initiating antiretroviral therapy: a cohort study. Rev Saude Publica[Internet]. 2020 [cited 2021 Dec 9];540:146. Available from: https://www.revistas.usp.br/rsp/article/view/180883
5. Cardoso MAS, Mugnol T, Dos Santos JM, Sperling GS, Diefenthäler LV, Garlet MA, et al. Perfil e qualidade de vida de mulheres que vivem com HIV. Holos. 2021;37 (3):1-16. https://doi.org/10.15628/holos.2020.10174
6. Viana AL, Bousquat A, Melo GA, Negri Filho A, Medina MG. Regionalization and Health Networks. Cien Saude Colet. 2018;23(6):1791-8. https://doi.org/10.1590/1413-81232018236.05502018
7. Ministério da Saúde (BR). 5 passos para a implementação do manejo da infecção pelo HIV na Atenção Básica: guia para gestores. 2014; 8 p.
8. Mendes EV. O cuidado das condições crônicas na atenção primária à saúde: o imperativo da consolidação da estratégia da saúde da família [Internet]. Brasília: OPAS; 2012[cited 2021 Oct 31]. 512 p. Available from: http://bvsms.saude.gov.br/bvs/publicacoes/cuidadocondicoes_atencao_primaria_saude.pdf
9. Ministério da Saúde (BR). Secretária de Vigilância em Saúde. Departamento de Vigilância Prevenção e Controle das Infecções Sexualmente Transmissíveis do HIV/Aids e das Hepatites Virais. Nota técnica N°. 208/09.
10. Rodrigues M, Maksud I. Abandono de tratamento: itinerários terapêuticos de pacientes com HIV/Aids. Saúde Debate [Internet]. 2017 [cited 2021 Nov 20];41(113):526-38: Available from: https://www.scielo.br/j/sdeb/a/qTKTctQZSKQKpDg8bfNJ6fQ/abstract/?lang=pt#
11. Mello CJFA, Amaral JCS, Costa MS, Cavalcante MNM, Rêgo NMS, Silva LMR, Amaral RR. Terapia Antirretroviral: principais causas de abandono no estado do Amapá. REAS [Internet]. 2020 [cited 2021 Nov 20];12(8):e3423. Available from: https://acervomais.com.br/index.php/saude/article/view/3423
12. Pereira TMV, Gir E, Santos AST. People living with HIV and changes in the daily routine a rising from the COVID-19 pandemic. Esc Anna Nery. 2021;25(spe):e20210176. https://doi.org/10.1590/2177-9465-EAN-2021-0176

13. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(suppl 6):349-57. https://doi.org/10.1093/intqhc/mzm042

14. Bardin, L. Análise de conteúdo. São Paulo: Edições 70 LDA, 2016.

15. Pinto MQC, Martins TCR, Mendonça JMG, Costa SM, Sampaio CA. Health from the perspective of people with HIV/Aids: a phenomenological view. Temas Saúde [Internet]. 2019 [cited 2021 Sep 4];19(3):484-96. Available from: https://temasemsaude.com/wp-content/uploads/2019/09/19328.pdf

16. Havas K, Douglas C, Bonner A. Closing the loop in person-centered care: patient experiences of a chronic kidney disease self-management intervention. Patient Prefer Adhrence. 2017;11:1963-73. https://doi.org/10.2147/PPA.S147831

17. Brandão BMGM, Angelim RCM, Marques SC, Oliveira RC, Abrão FMS. Living with HIV: coping strategies of seropositive older adults. Rev Esc Enferm USP. 2020;54:e03576. https://doi.org/10.1590/S1980-220X2018027603576

18. Vaz EMC, Collet N, Cursino EG, Forte FDS, Magalhães RKBP, Reichert APS. Care coordination in Health Care for the child/ adolescent in chronic condition. Rev Bras Enferm. 2018;71(Suppl 6):2612-9. https://doi.org/10.1590/0034-7167-2017-0787

19. Furlan MCR, Santos AG, Marcon SS. Relationships with the health professional in the treatment of tuberculosis: patients' perception. Rev Enf Centro-Oeste Mineiro 2017;7:e1934. https://doi.org/10.19175/recom.v7i0.1934

20. Pereira CR, Szwarcwald CL, Damacena GN. A discriminação de pessoas vivendo com HIV/aids no trabalho: uma análise quantitativa e qualitativa. P2P Inovação. 2019;6(1):60-82. https://doi.org/10.21721/p2p.2019v6n1

21. Russell S, Martin F, Zalwango F, Namukwaya S, Nalugya R, Muhumuza R, et al.Finding Meaning: HIV Self-Management and Wellbeing among People Taking Antiretroviral Therapy in Uganda. Plos One. 2016;11(1):e0147896. https://doi.org/10.1371/journal.pone.0147896

22. Ferreira DC, Darmont MQR. Grupo de jovens de transmissão vertical vivendo com HIV/aids: a construção de um espaço de sociabilidade na tecedura de uma rede de proteção social. Rev Human Inov [Internet]. 2021 [2021 Oct 20];8(39):199-211. Available from: https://revista.unitins.br/index.php/humanidadeseinovacao/article/view/5752

23. Ferreira J. Chronic noncommunicable diseases and dilemmas of care: the theory of negotiated order revisited. Saúde Soc. 2020;29(4):e190149. https://doi.org/10.1590/S0104-12902020190149

24. Nascimento AMV, Santos CAO, Santos DD, Medeiros MK, Fagundes GRS, Pereira BS, et al. Support network for homosexuals living with HIV/aids: an integrative review. Res, Soc Develop. 2020;9(10):e4279108792. https://doi.org/10.33448/rsd-v9i10.8792

25. Melo EA, Maksud I, Agostini R. HIV/aids management at the primary care level in Brazil: a challenge for the Unified Health System? Rev Panam Salud Publica. 2018;42:e151. https://doi.org/10.26633/RPSP.2018.151

26. Lima MCL, Pinho CM, Silva MAS, Dourado CARO, Brandão BMGM, Andrade MS. Perception of nurses about the decentralization process of HIV/Aids care: rapid test. Esc Anna Nery. 2021;25(4):1-6. https://doi.org/10.1590/2177-9465-EAN-2020-0428

27. Zambenedetti G, Silva Ran. Decentralization of health care to HIV-AIDS for primary care: tensions and potentialities. Physis Rev Saúde Coletiva. 2016;26(3):785-806. https://doi.org/10.1590/S0103-73312016000300005

28. Bhandari B, Narasimhan P, Vaidya A, Subedi M, Jayasuriya R. Barriers and facilitators for treatment and control of high blood pressure among hypertensive patients in Kathmandu, Nepal: a qualitative study informed by COM-B model of behavior change. BMC Public Health. 2021;1524. https://doi.org/10.1186/s12889-021-11548-4

29. Teixeira CP, Guilam MCR, Machado MFAS, Gomes MQ, Almeida PF, et al. Atenção, Educação e Gestão: Produções da Rede Profsaúde. Associação Brasileira da Rede UNIDA[Internet]. 2020 [cited 2021 Nov 5]. 252 p. Available from: https://editora.redeunida.org.br/wp-content/uploads/2020/12/Atencao-Educacao-e-Gestao-Producoes-da-Rede-Profsaude-volume-2.pdf

30. Simoni JM, Beima-Sofie K, Wanje G, Mohamed ZH, Tapia K, McClelland RS, et al. "Lighten This Burden of Ours": acceptability and preferences regarding injectable antiretroviral treatment among adults and youth living with HIV in Coastal Kenya. J Int Assoc Provid AIDS Care (JIAPAC). 2021:20. https://doi.org/10.1177/23259582211000517

31. Mendez RDR, Santos MA, Wysocki AD, Ribeiro BDAB, Stauffer LF, Duarte SJH. Cardiovascular risk stratification among hypertensive patients: the influence of risk factors. Rev Bras Enferm. 2018;71(4):1985-91. https://doi.org/10.1590/0034-7167-2017-0528

32. Leadebal ODCP, Medeiros LB, Nascimento JA, Monroe AA, Nogueira JA. Classification of clinical risk in people with AIDS followed up in specialized care. Rev Bras Enferm. 2017;71(5):1235-42. https://doi.org/10.1590/0034-7167-2017-0559

33. Parente JS, Azevedo SL, Moreira LFA, Abreu LM, Souza LV. O impacto do isolamento social na pandemia COVID-19 no acesso ao tratamento do HIV e serviços de prevenção. Pesqui Soc Desenvolv. 2021;10(1):e28110111692. https://doi.org/10.33448/rsd-v10i1.11692