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Beyond active search: motivations for returning to HIV treatment

Para além da busca ativa: motivações para retorno ao tratamento de HIV

Más allá de la búsqueda activa: motivaciones para volver al tratamiento del VIH

Juliete Bispo dos Santos Mandu[I]; *Sonia Silva Marcon*[II]; *Guilherme Oliveira de Arruda*[I];
Adriana Carla Garcia Negri[I]; *Ivair Moura de Souza*[I]; *Elen Ferraz Teston*[I]

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

ABSTRACT

Objective: to identify factors that influence the decision to abandon treatment or foster a willingness to resume it, from the perspective of persons living with HIV. **Method:** this qualitative study was carried out between April and August 2021 in an outpatient service, after approval by the research ethics committee. Data were collected by consulting medical records and interviewing 24 users, and were treated by content analysis. **Results:** reasons for abandoning treatment most frequently mentioned were the social isolation imposed by the pandemic, difficulty in accessing or commuting to the service, and the drugs' side effects. The motivations for returning to the service were the desire to feel healthy, play social roles, cultivate family ties, recognize that he has overcome worse phases and the feeling of added value after active search. **Final considerations:** the findings point to the importance of individualized care to understanding the motivations for returning to treatment, which can inform the planning of active search actions.

Descriptors: HIV; Nursing Care; Treatment Adherence and Compliance; Medication Adherence; Motivation.

RESUMO

Objetivo: apreender aspectos que influenciam no abandono do tratamento e que mobilizam a disposição para retomá-lo, na perspectiva de pessoas que vivem com HIV. **Método:** estudo qualitativo, realizado em um serviço ambulatorial, com dados coletados entre abril e agosto de 2021, após aprovação pelo Comitê de Ética em Pesquisa, mediante consulta aos prontuários e entrevistas com 24 usuários, submetidas à análise de conteúdo. **Resultados:** os motivos para o abandono do tratamento referidos com maior frequência foram isolamento social imposto pela pandemia, dificuldade de acesso/locomoção até o serviço e efeitos colaterais dos medicamentos. O desejo de sentir-se saudável, desempenhar papeis sociais, cultivar laços familiares, reconhecer que já superou fases piores e o sentimento de mais valia após busca ativa, foram as motivações para retorno ao serviço. **Considerações finais:** os resultados apontam a importância do atendimento individualizado para conhecer as motivações de retorno ao tratamento as quais oferecem subsídios para o planejamento de ações de busca ativa.

Descritores: HIV; Cuidados de Enfermagem; Cooperação e Adesão ao Tratamento; Adesão à Medicação; Motivação.

RESUMEN

Objetivo: comprender aspectos que influyen en el abandono del tratamiento y que movilizan la voluntad para retomarlo, en la perspectiva de las personas que viven con VIH. **Método:** estudio cualitativo, realizado en un servicio de consulta externa, con datos recolectados entre abril y agosto de 2021, después de la aprobación del Comité de Ética en Investigación, mediante consulta de historias clínicas y entrevistas con 24 usuarios, sometidos a análisis de contenido. **Resultados:** los motivos de abandono del tratamiento mencionados más frecuentemente fueron el aislamiento social impuesto por la pandemia, la dificultad de acceso/traslado al trabajo y los efectos secundarios de los medicamentos. El deseo de sentirse saludable, desempeñar roles sociales, cultivar lazos familiares, entender que ha superado fases peores y la sensación de plusvalía luego de una búsqueda activa, fueron las motivaciones para volver al servicio. **Consideraciones finales:** los resultados apuntan hacia la importancia de la atención individualizada para comprender las motivaciones de retorno al tratamiento, que ofrecen subsidios para la planificación de acciones de búsqueda activa.

Descriptores: VIH; Atención de Enfermería; Cumplimiento y Adherencia al Tratamiento; Cumplimiento de Medicación; Motivación.

INTRODUCTION

Latin America is the third most affected global region by the Human Immunodeficiency Virus (HIV). However, a quarter of those infected do not know their diagnosis and 40% do not have access to antiretroviral therapy (ART)[1]. Approximately 920,000 people were living with HIV (PLHIV) in Brazil in 2019, of which 821,000 (89%) were diagnosed; 772 thousand (84%) were linked to some health service and 682 thousand (74%) linked to services, with ART coverage of 69% among all PLHIV[2]. It should be noted that the Southeast region had the highest frequency of HIV infection notification in 2020, and the Midwest region had the lowest frequency (9.8%)[3].

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

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Strategies were developed to expand access to the rapid test, to connect to the health service, for treatment retention and adherence with the aim of favoring care and monitoring of PLHIV. For this to happen, the 95-95-95 target was proposed, which consists of diagnosing 95% of PLHIV, treating 95% of them with antiretroviral drugs and achieving viral suppression in 95% of those on treatment by 2030[4].

Furthermore, information systems were developed which contributed to monitoring care provided to PLHIV, such as the Medication Logistic Control System (*Sistema de Controle Logístico de Medicamentos - SICLOM*), which makes it possible to monitor ART withdrawal[5]. This follow-up enables identifying people who are abandoning treatment - a situation in which a user does not obtain antiretroviral drugs for at least three months after the scheduled date and/or does not return to consultations at the health service within six months[6].

Several factors can influence treatment abandonment by PLHIV, such as existing barriers to providing healthcare, fear of unwanted disclosure of the diagnosis, long waiting times at health units to obtain medication, side effects, need for periodic laboratory monitoring and family and/or social responsibilities that inhibit attendance at the health service[7]. Aspects of a personal nature are also noteworthy, such as low education level, unemployment, low income, alcohol consumption, poor diet, self-efficacy expectancy relationships and a lack of knowledge about HIV[7-10].

Although the use of ART as prescribed can sufficiently reduce or suppress an individual's viral load, which is essential for maintaining health of PLHIV[11], a study carried out in the interior of São Paulo showed an adherence rate to ART of 62%[12]. In turn, a cohort study which evaluated non-adherence to ART in reference services in Pernambuco found an adherence rate of 85.5%[13].

In this scenario, care practices with a consensual approach aim to re-establish the link between users and the health service and minimize limiting factors for adherence[7]. An active search through telephone contact constitutes a strategy which enables creating a bond between PLHIV and the health service, which is an easy and quick method that provides direct contact in a less invasive way[7]. Telephone use is indicated as a form of support for care actions for PLHIV, as it contributes to improve adherence to ART and the link to the health service[14]. A study carried out at a clinic in South Africa, which cares for PLHIV in rural areas, showed that sending weekly text messages had a positive effect on adherence to ART[15].

Faced with this, the question posed in this study is: What is the perception of PLHIV about treatment abandonment and its consequences? Which factors can motivate a return to treatment after an active search? In order to answer these questions, the present study aimed to capture aspects that influence treatment abandonment and that mobilize the willingness to resume it from the perspective of people living with HIV.

METHOD

This is an exploratory descriptive study with a qualitative approach conducted in a reference outpatient clinic for infectious parasitic diseases located in a capital in the Midwest region of Brazil, following the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ)[16].

The outpatient clinic is a state reference service for people living with HIV/AIDS, viral hepatitis and other infectious and parasitic diseases, which works as a backup for the outpatient clinic and infectology ward of a University Hospital. It has nine unconventional hospital beds (day hospitalization), which allows daily assessment and treatment of clinically stable PLHIV. It has an average attendance of 60 patients per week, from Monday to Friday, in the morning and afternoon periods. An average of 12 medical consultations with an infectologist are available daily. Nurses, nursing technicians, psychologists, social workers, pharmacists and volunteer academics in the health area (medicine, nursing) work at the clinic.

PLHIV who had abandoned treatment, aged 18 years or older, identified from the relationship obtained in *SICLOM* participated in the study. A total of 284 PLHIV were identified in this condition based on the medical records among the 1,785 registered in the service, thereby obtaining their telephone contacts. During consultation of the medical records, it was found that 41 PLHIV had died, 26 had already resumed treatment (*SICLOM* outdated), two had used ART as pre-exposure prophylaxis (PrEP), one had a negative test result and seven had a double record.

Thus, 207 users were considered eligible, but it was not possible to make contact with 175 of them after at least three attempts on different days and times. Of the 32 users contacted, two were not interested in resuming treatment and four scheduled an appointment depending on availability, but did not attend. Of the 26 users who attended the nursing consultation, two declined to participate in the study. Therefore, 24 users were included in the study.

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The active search by telephone contact and all other activities related to data collection were performed in a private room at the outpatient clinic by the study's main research nurse with experience in collecting qualitative data, and who had no relationship with the participants. During the contact, it was confirmed whether the individual was indeed abandoning treatment, and if so, an attempt was made to sensitize them as to the importance of resuming it, offering the possibility of scheduling a nursing consultation at the outpatient clinic. In addition to a nursing consultation on this return visit, laboratory tests were also collected to identify the viral load and TCD4$^+$ lymphocytes, according to the Clinical Protocol and Therapeutic Guidelines (*Protocolo Clínico e Diretrizes Terapêuticas – PCDT*)[17], which recommend that these tests be performed every six months. Data referring to laboratory tests (viral load and TCD4$^+$ lymphocytes) were obtained from *Laudo Aids* (a system which contains the viral load and TCD4$^+$ lymphocytes results), considering the last tests performed before treatment abandonment.

At the end of the nursing consultation (also conducted by the main researcher), the PLHIV were informed about the study and invited to participate in it. Those who accepted after signing the Informed Consent Form were interviewed on the same day or on another day, depending on availability.

Thus, semi-structured interviews were performed from April to August 2021 in a reserved room in the outpatient clinic, and lasted an average of 25 minutes, being audio-recorded. A script prepared by the authors based on the study objective was used, consisting of two parts. The first contained the guiding question: What were the reasons that made you return to treatment? The second part consisted of questions related to the sociodemographic characteristics of the participants, and some supporting questions that included the following dimensions: factors that influenced abandonment and return to treatment, satisfactory/unsatisfactory experiences with the health service and the perception of abandonment of treatment. Before starting the interviews, the data collection instrument was discussed and improved in the research group responsible for conducting the study.

A thematic content analysis was subsequently performed after transcribing the interviews in full, which followed the three proposed steps: a) pre-analysis: the material was explored by a floating and exhaustive reading of the speeches to identify strengths in relation to the study objective; b) material exploration: the codes were formulated, which objectively simplified the obtained data; c) the interpretation stage: the statements were organized into two categories identified as: "Motivators for returning to treatment" and "Ambivalence towards HIV treatment" and then proceeded to the inferences, interpretation and discussion with the current literature[18].

The study protocol was evaluated and approved by the Research Ethics Committee of the signatory institution. It was decided to call the participants by the letters M for males and F for females, followed by the number corresponding to the chronological order in which the interviews were conducted, the diagnosis time length, and the amount of time of treatment abandonment in days in order to maintain anonymity regarding the participants' identity; for example: M1.5 years of diagnosis, 243 days of abandonment.

RESULTS

The 24 study participants were aged between 23 and 63 years, 12 of them female. Regarding their education level, seven had elementary education at most, 13 had high school education and four had higher (university) education. The time since diagnosis varied between two and 23 years (mean=8.5 years).

Figure 1 shows the time of treatment abandonment and the main reasons shown by the participants for this occurrence. Complementarily, information is also presented on laboratory tests that attest to the clinical conditions before abandonment and when returning to the service.

From the information presented, it is observed that the treatment abandonment time ranged from 114 to 1249 days (mean=334 days) and that the most frequently mentioned reasons were the social isolation imposed by the pandemic (n=8), the difficulty of access/commuting to the service (n=6) and side effects of the medication (n=5).

Regarding clinical conditions before abandoning treatment, half of the participants had an undetectable viral load or less than the minimum limit, but upon returning to the service, most of them (n=20) showed an increase in viral load and half had a decrease severe lymphocyte count (below 200 cells/mm^3).

During the interviews, most participants (n=18) reported that they had already experienced abandonment and returned to treatment, and six of them reported that they had already been hospitalized due to worsening health conditions.

Furthermore, six reported that they had some worrying symptom during the abandonment period such as weight loss, sore throat, pain in the lower limbs, weight gain, weakness and tiredness.

			Before abandonment		**Upon return to the service**	
Code	**Abandonment time (in days)**	**Reason for abandonment**	**Vl**	**TCD4^{+}**	**Vl**	**TCD4^{+}**
E1	243	Medication side effects; weight gain.	1962	Moderate	45	Serious
E2	621	Access difficulty (moving) and bond with the health service.	Undetectable	Not significant	3875	Not significant
E3	356	Pandemic; access difficulty (locomotion).	76	Not significant	< minimum limit	Not significant
E4	356	Pandemic. Access difficulty (locomotion).	Undetectable	Moderate	10952	Advanced
E5	307	Pandemic.	45	Serious	48090	Serious
E6	384	She found the Bible and felt that she was healed.	Undetectable	Advanced	17469	Not significant
E7	326	Depression and anxiety.	58157	Serious	95919	Serious
E8	119	Does not accept the diagnosis.	1283	Not significant	505	Not significant
E9	114	Too lazy to go to the service and does not care about the diagnosis.	Undetectable	Not significant	21560	Not significant
E10	1249	Ashamed to go to the health service.	116870	Serious	90407	Serious
E11	274	Pandemic.	Undetectable	Not significant	369259	Serious
E12	148	Pandemic.	508	Not significant	23177	Not significant
E13	500	Discouragement, change of medication and schedule.	4976	Moderate	95290	Advanced
E14	125	Medication side effects; does not accept the diagnosis.	Undetectable	Not significant	1595	Not significant
E15	391	Medication side effects.	Undetectable	Advanced	Undetectable	Not significant
E16	159	Pandemic; Difficulty scheduling an appointment.	< minimum limit	Serious	25580	Serious
E17	327	Access difficulty (locomotion).	992	Advanced	2275	Advanced
E18	421	Access difficulty (locomotion).	< minimum limit	Advanced	58963	Serious
E19	305	* Reports that they had medications at home, for this reason they did not return to the health service.	Undetectable	Not significant	Undetectable	Not significant
E20	182	*Pandemic. Discouragement at having to go to the health service alone.	< minimum limit	Serious	< minimum limit	Serious
E21	561	I work.	725	Advanced	421158	Serious
E22	226	Medication side effects; Despondency after wife's death in 2000.	769	Serious	134171	Serious
E23	199	I work; Pandemic.	< minimum limit	Moderate	10736	Serious
E24	121	Side effect of medication - difficulty sleeping.	576	Advanced	3855	Serious

Source: participants' medical records. **Legend:** Vl: Viral load; PLHIV – person living with HIV; *350-499 cells/mm^3; ** >500 cells/mm^3; *** < 200 cells/mm^3; **** 200-349 cells/mm^3

FIGURE 1: Clinical characteristics/biological markers of research participants before and after abandoning treatment and the reasons that led to abandonment. Campo Grande, MS, Brazil, 2021.

The two categories that emerged from the data analysis are presented below.

Motivators for returning to treatment

Carrying out the treatment has significant purposes for the interviewees which are directly linked to their lives, such as a feeling of being and feeling well, the possibility of better knowing what their state of health is and of living better, the possibility of fulfilling daily commitments and playing social roles, as well as cultivating family ties, as shown in Figure 2.

Thematic axes	**Speeches/reports**
Desire to live and feel good	*What motivates me to return to treatment is to be well. Just like today I said when I was coming "today I'm going there, I'm going to take the medicine, I'm going to do everything right so I can travel" (laughs). Because I want to go out, be well, because I travel on business, but I know that my health is not 100% today. (M1, 5 years of diagnosis, 243 days of abandonment)* *The interest in knowing how my health is, my organism after months without taking medication because I had normal TCD4 lymphocytes, well, before the viral load was undetectable. So, knowing how I am and going back to having a healthy life. (F14, 2 years of diagnosis, 125 days of abandonment)* *[...] we need to get well and for that we need to do the treatment even though it is not easy, even without wanting to be here, we make a great effort to feel normal, we need to find some way to continue the treatment. (M16, 21 years of diagnosis, 159 days of abandonment)* *The treatment is the only way for me, without drinking the cocktail it's like a lighted candle burning and when it reaches the end it goes out. So I was aware that this disease is undermining me, my immunity is going down, if the candle was small I would live up to a certain point. My motivation is to live, I like to live, I like life. (M22, 23 years of diagnosis, 226 days of abandonment)*
Concern for the family	*He (my son) is the motivation for me to return to treatment. If I get sick or hospitalized, who will take care of him? A mother is a mother, like me, no one will take care of him like me. (F15, 5 years of diagnosis, 391 days of abandonment)* *The other time it was because I got sick, otherwise I wouldn't have come. Now it was for my son, I see that he is becoming more and more alone, there is only me, my mother and my sister. (F11, 18 years of diagnosis, 274 days of abandonment)* *My eldest daughter motivates me a lot, she says a lot "It's not your fault you have this, but you have to do it, think about us, about me and our two brothers". (F21, 3 years of diagnosis, 561 days of abandonment)*
Believe you can overcome again	*And today I think, the worst phase I overcame, why not now? Now I only take two pills a day. Even if it changes now because I stopped, it won't be the same medicine, same scheme. (M1, 5 years of diagnosis, 243 days of abandonment)*
Feeling welcome and cared for – an active search makes a difference	*You know when you feel like someone cares about you, welcomed. I was very happy, I never imagined that they would call me. And you feel comfort, that assurance in the person's voice, even without knowing the person. Then I said "I'm going to fix my life, because someone still wants to take care of me." (laughs) (M1.5 years of diagnosis, 243 days of abandonment)* *I didn't expect the hospital to contact me. So when you called me, I thought it was cool because of the care, as much as it is up to us patients to have that care, even though I had abandoned it, the hospital had gone after it and wanted to know, I found it interesting. (F14, 2 years of diagnosis, 125 days of abandonment)* *The contact manages to bring us closer together, we feel welcomed when we see that there is someone thinking about their health [...] having this closeness. All of this makes it very different [...] this process of human contact makes a total difference [...] and I felt very comfortable and that's why I came back. (M16, 9 years of diagnosis, 159 days of abandonment)*

FIGURE 2: Thematic axes and reports of research participants that originated category 1. Campo Grande, MS, Brazil, 2022.

Ambivalence towards HIV treatment

It is observed in the reports presented in Figure 3 that the study participants have an ambivalence in relation to the HIV treatment, being configured on the one hand by awareness of the need to follow the proposed treatment. In this sense, they even make recommendations on its importance. On the other hand, they are resistant to properly adhere to the treatment.

Thematic axes	**Speeches/reports**
Importance of not abandoning treatment and recommendations for other PLHIV	*I would like to tell the other PLHIV that they do the treatment correctly, take the medicine, because many times you abandon it and then come back with many problems. To have a healthy life you have to take it. (F6, 12 years of diagnosis, 384 days of abandonment)* *Don't make the mistake of leaving (laughs). I've seen a lot of people who didn't take it for 6 months and came home a rag, mulambo. It's really stupid to abandon it, I abandoned it. (M18, 21 years of diagnosis, 421 days of abandonment)* *Don't give up like I did, don't give up because the final stage is ugly, [...] it's too painful and if we take care of it, we have a whole life ahead of us. (F14, 2 years of diagnosis, 125 days of abandonment)* *The only message is: be sure to do the treatment, because it's good for us, it's good for society that you will be helping to not transmit the disease, having a normal life, it doesn't change anything. The only thing that changes is knowing that you have to live with the virus. (M5, 2 years of diagnosis, 307 days of abandonment)*

FIGURE 3: Thematic axis and reports that originated category 2. Campo Grande, MS, Brazil, 2022.

DISCUSSION

As pointed out by the participants, although the treatment abandonment time may have some relation to the pandemic moment experienced during the data collection period, one cannot fail to consider that the cause mentioned by three of them was related to difficulty in accessing the service, especially for the five with more than one year of abandonment.

This problem has already been pointed out in other studies which found difficulty in scheduling appointments, exams and access to medication (management problem)[8-10]. Faced with these care challenges, the importance of a shorter time interval between consultations, home visits by the Family Health Strategy team and a good relationship between health service professionals and users[9] are highlighted. In addition, it is believed that care strategies which allow the user to alternate follow-up between the specialized service (for consultations and specific exams) and the Basic Health Unit close to their residence (for regular follow-up and withdrawing medication), mediated by referral and counter-referral actions can positively influence adherence to treatment.

Other aspects reported by participants in this study as reasons for abandoning treatment have also been raised in other studies. The literature points out that they can be of a personal nature when it involves feelings of fear, shame, lack of a support network, non-acceptance of the diagnosis and depression[19-21]; and related to treatment characteristics such as side effects of medications, excess of pills taken per day and difficulty in linking with the health service. In addition, social and economic factors, such as the stigma that still exists in relation to PLHIV[7], the lack of resources and the difficulty of getting around also constitute barriers to accessing the health service[22].

The effects of abandoning treatment on health can be identified when comparing the values / results of laboratory tests before abandonment and when returning to the service, since the increase in viral load levels and the worsening of the immune status of the participants shows that most of them have compromised immune systems. This is because the individual is susceptible to diseases such as pneumococcal pneumonia, pulmonary tuberculosis, herpes zoster, oropharyngeal candidiasis and Kaposi's sarcoma when the $TCD4^+$ lymphocyte count is between 200 and 500 cells/mm^3; and below 200 cells/mm^3 they are susceptible to opportunistic diseases such as pneumocystosis and toxoplasmosis. Toxoplasmosis and cryptococcosis can occur with critical counts below 100 cells/mm^3, which can lead to death due to impaired immune response against microorganisms[23,24].

Therefore, the purpose of treatment is to improve quality of life and prolong survival by reducing the viral load and reconstituting the immune system. Thus, ART should be initiated regardless of the TCD4+ lymphocyte count in order to break the chain of transmission[25].

The following reasons that mobilized the participants to show interest in adhering to ART again were mentioned: the need to be and feel good, the possibility of better knowing what their health status is and living better, fulfilling daily commitments and playing social roles, as well as cultivating family ties. These results corroborate those of a study carried out in Malawi with PLHIV who returned to treatment within 60 days, which pointed out that the motivation for returning was the desire to preserve their health. However, in many cases, the interviewees also reported having been influenced by concern for the family and fear of the disease. It is noteworthy that in these cases they also had the social support of family members[26].

Thus, family support, whether for adherence to ART or for returning to treatment after abandonment, is a fundamental factor. This is because the support network can minimize the impacts caused by the disease and enable a broader understanding of the fears and anxieties that the individual is facing. A study carried out in Kampala, Uganda, with young people living with HIV revealed that the relationship with the family and sometimes with other young people who experience the same health condition creates an important support network in adherence to ART[27].

The participants also highlighted that the fact of having overcome the initial phase of (with) living with the diagnosis, sometimes considered as the worst, in particular because it entails a series of fears such as social judgment and stigma, can also favor willingness to perform the treatment. Studies show that overcoming the initial treatment is to transform the situation, especially the diagnosis phase, and point out that the first year of treatment has the highest dropout rate due to side effects, difficulty in acceptance, problems with confidentiality of the diagnosis, prejudice, discrimination, lack of support network, and concerns about financial life[28,29]. It is noteworthy that the participants' reports enable identifying how much the phone call for the active search contributed to a feeling of added value, which certainly favored their willingness and mobilization in wanting to return to the service.

Thus, different strategies with the aim of reducing dropout rates, favoring adherence and retention to treatment and improving care for PLHIV can be used by health professionals. For example, a study carried out in Uganda with PLHIV showed that the use of text messages and calls as a means of health education led to greater adherence to medication, strengthening of bonds with professionals and increased knowledge about healthcare[30].

In this same direction, a study carried out in Fortaleza, CE, Brazil, with PLHIV who had access to the internet and WhatsApp showed that the exchange of messages in real time made it possible to clarify doubts with health professionals. Furthermore, the PLHIV referred to the importance of messages as a reminder to perform healthcare and as a way of encouraging them to remain in treatment[31].

In this context, the active search strategy, whether by phone call or text messages, aims to create and maintain a bond between the user and the health service, identify the current health situation and obtain the necessary information to subsidize implementing interventions which favor connection, retention and adherence to treatment[32]. It should be noted that communication generates trust, freedom and bonding, which constitute fundamental elements for the patient to feel welcomed and expose their fears and anxieties.

A study carried out with Primary Health Care (PHC) professionals in the state of Paraíba, Brazil, pointed out that care for individuals with chronic conditions requires long-term individualized actions, and in order for this to occur, it is necessary to optimize active search strategies such as home visits, as they allow for dialogue and knowledge of the patient's and family's reality[33]. In addition, health education and disease prevention actions *in loco* enable identifying risk factors and elaborating coping strategies which favor the maintenance of treatment[34].

However, a study carried out in Rio de Janeiro with professionals and PLHIV in treatment abandonment showed that the active search is not a frequent practice in health services[35], even though it is a strategy recommended by the Ministry of Health of Brazil[36] for other conditions, such as tuberculosis.

When asked about the need for treatment, the participants of the present study sometimes showed ambivalence, because although they had abandoned it, when they returned to the service they demonstrated the importance of using ART to maintain health and quality of life. In addition, they reported that even with the numerous changes in the routine that HIV treatment causes, adherence is the best method to live with less damage, and they even recommend this to other PLHIV.

A study with women deprived of liberty and who had HIV in Salvador, BA, Brazil, revealed that they recognized the need to adhere to treatment, but faced some barriers such as the feeling of fear of revealing the diagnosis and suffering prejudice in the environment in which they were inserted[37].

Likewise, the participants' reports herein allow us to infer that they understand the importance of treatment and follow-up in order to have quality of life. However, one cannot fail to consider that there are essential factors for adequate planning of actions to be implemented over the years with a view to continuous care. However, it should be noted that knowing the factors related to treatment abandonment and the strategies employed to rescue PLHIV in abandonment highlights the need for intersectoral articulation[38], and above all willingness and commitment on the part of the professionals involved.

Study limitations

As a limitation of this study, the impossibility of contacting the majority of PLHIV identified as abandoning treatment can be pointed out due to the outdated telephone number registered in the medical records, impairing potential generalizations of the results. This fact indicates that it is necessary to adopt other strategies associated with telephone contact for better understanding of the reasons that lead PLHIV to abandon treatment.

FINAL CONSIDERATIONS

The results of this study allowed us to understand that the main reasons for abandoning treatment from the perspective of PLHIV were the social isolation imposed by the pandemic, the difficulty in accessing/getting to the service and the side effects of the medications.

In addition to the active search, the feeling of being and feeling well, the possibility of better knowing what their health status is and living better, the possibility of complying with daily commitments and playing social roles, as well as cultivating family ties, and also the fact that they recognize that they have already overcome worse phases were among the aspects that mobilized their willingness to return to the service.

These aspects can contribute to qualifying the care offered to PLHIV in a situation of treatment abandonment, since adherence to the treatment of chronic conditions, such as HIV infection, remains an important challenge for health professionals.

Moreover, these aspects should be considered when approaching this population, not only at the beginning of treatment, but also in all their interactions with health professionals, especially in specialized services. Likewise, it is important that professionals recognize and do not trivialize the ambivalence of feelings regarding HIV treatment in their interactions with PLHIV. Individualized care is relevant, which allows knowing the reality and experiences lived by PLHIV, not only in relation to treatment, but also in their life context.

In this sense, it is essential that health services know the reasons which lead registered PLHIV to abandon treatment and also reasons which can encourage them to resume it. To do so, the use of strategies such as the active telephone search is suggested, which, in addition to being low cost and easy to implement in the routine of the service, is accessible, fast and effective in reestablishing, maintaining and strengthening the bond, as well as in rescuing PLHIV who are not attending the health service or adhering to the proposed treatment.

This strategy also makes it possible to understand the current situation of the individual, and when necessary, to intervene in order to minimize the cases of treatment non-adherence/abandonment. Therefore, it is necessary that the implementation focus is PLHIV, considering all their uniqueness and health conditions and that ethical aspects are respected, so that the rights of the individual, as a citizen, are not violated.

REFERENCES

1. UNAIDS. Relatório global do UNAIDS. 2020 [cited 2021 Dec 22]. Available from: https://www.unaids.org/sites/default/files/media_asset/2020_global-aids-report_en.pdf.
2. Ministério da Saúde (Br). Departamento de Vigilância, Prevenção e Controle das Infecções Sexualmente Transmissíveis, do HIV/AIDS e das Hepatites Virais, Secretaria de Vigilância em Saúde, Ministério da Saúde. Relatório de monitoramento clínico do HIV 2020. 2021 [cited 2022 Dec 11]; 113 p. Avalilable from: https://bvsms.saude.gov.br/bvs/publicacoes/relatorio_monitoramento_clinico_hiv_2020.pdf.
3. Ministério da Saúde (Br). Departamento de Vigilância Prevenção e Controle das Infecções Sexualmente Transmissíveis do HIV/Aids e das Hepatites Virais. Boletim Epidemiológico HIV/Aids 2021. HIV Aids Bol Epidemiológico. 2021 [cited 2021 Jan 11]; 72 p. Available from: http://www.aids.gov.br/pt-br/pub/2021/boletim-epidemiologico-hivaids-2021.
4. UNAIDS. Fast-Track—Ending the AIDS epidemic by 2030. 2014 [cited 2021 Jan 11]. Available from: https://www.unaids.org/en/resources/documents/2014/JC2686_WAD2014report.

5. Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Vigilância, Prevenção e Controle das Infecções Sexualmente Transmissíveis, do HIV/AIDS e das Hepatites Virais. Protocolo Clínico e Diretrizes Terapêuticas para o Manejo da Infecção pelo HIV em adultos. Brasília. 2018 [cited 2021 Dec 21]. p.412. Available from: http://www.aids.gov.br/pt-br/pub/2013/protocolo-clinico-e-diretrizes-terapeuticas-para-manejo-da-infeccao-pelo-hiv-em-adultos.
6. Brasil. Ministério da Saúde. 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. 2009 [cited 2021 Dec 27]. Available from: http://www.aids.gov.br/pt-br/legislacao/nota-tecnica-no-2082009.
7. Liao B, Zhang X, Wang J, Liu J, Liang J, He W, et al. Analysis of factors associated with dropping-out from HIV antiretroviral therapy in Kunming City, China. BMC Infect Dis. 2019 [cited 2022 Dec 19]; 19:1043. DOI: https://doi.org/10.1186/s12879-019-4658-z.
8. Cabral JR, Cabral LR, Moraes DCA, Oliveira ES, Freire DF, Silva FP, et al. actors associated with self-efficacy and adherence to antiretroviral therapy in people with hiv: cognitive social theory. Ciênc. cuid. saúde. 2021 [cited 2022 Dec 19]; 20:e58781. DOI: https://doi.org/10.4025/ciencuidsaude.v20i0.58781.
9. Carvalho PP, Barroso SM, Coelho HC, Penaforte FRO. Factors associated with antiretroviral therapy adherence in adults: an integrative review of literature. Ciênc Saúde Colet. 2019 [cited 2022 Dec 19]; 24(7):2543-55. DOI: https://doi.org/10.1590/1413-81232018247.22312017.
10. Seidl, EMF, Remor E. Treatment adherence, resilience and illness perception in people with HIV. Psicol teor pesqui. 2020 [cited 2022 Dec 16]; 36:e36nspe6. DOI: https://dx.doi.org/10.1590/0102.3772e36nspe6.
11. Feldman MB, Tran TT, Boucher LM, Abdelqader F, Raker AR, Hile SJ. A process and impact evaluation of a peer-led HIV self-management program. Eval Program Plann. 2022 [cited 2022 Dec 17]; 96:102175. DOI: https://doi.org/10.1016/j.evalprogplan.2022.102175.
12. Bomfim, IGO, Santos SS, Napoleão AA. Adherence to antiretroviral therapy in people living with HIV/AIDS: a cross-sectional study. AIDS Patient Care STDS. 2022 [cited 2022 Dec 18]; 36(7): 278-84. DOI*:* https://doi.org/10.1590/1516-3180.2019.0212170919.
13. Fonseca Lima RA, Miranda-Filho DB, Montarroyos UR, Cavalcanti ATAE, Ximenes RAA. Adherence to antiretroviral therapy and factors associated with non-adherence: a cohort study at two referral services in Brazil. AIDS Care. 2022 [cited 2022 Dec 20]; 31:1-9. DOI: https://doi.org/10.1080/09540121.2022.2029814.
14. Santos VF, Costa AKB, Lima ICV, Alexandre HO, Gir E, Galvão MTG. Use of the telephone for accessing people living with HIV/AIDS to antiretroviral therapy: systematic review. Ciênc Saúde Colet. 2019 [cited 2021 Dec 29]; 24(9):3407-16. DOI: https://doi.org/10.1590/1413-81232018249.31112017.
15. Georgette N, Siedner MJ, Petty CR, Zanoni BC, Carpenter S, Haberer JE. Impact of a clinical program using weekly Short Message Service (SMS) on antiretroviral therapy adherence support in South Africa: a retrospective cohort study. BMC med inform decis mak. 2017 [cited 2022 Jan 10]; 17(1):18. DOI: https://dx.doi.org/10.1186%2Fs12911-017-0413-9.
16. 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 [cited 2022 Jan 03]; 19(suppl 6):349-57. DOI: https://doi.org/10.1093/intqhc/mzm042.
17. Ministério da Saúde (Br). Departamento de Vigilância Prevenção e Controle das Infecções Sexualmente Transmissíveis do HIV/Aids e das Hepatites Virais. Boletim Epidemiológico HIV/Aids 2020. HIV Aids Bol Epidemiológico. 2020 [cited 2021 Dec 08]; 68p. Available from: http://www.aids.gov.br/pt-br/pub/2020/boletim-epidemiologico-hivaids-2020.
18. Bardin, L. Análise de conteúdo. São Paulo: Edições 70 LDA, 2016.
19. Goulart S, Meirelles BHS, Costa VT, Pfleger G, Silva LM. Adherence to antiretroviral therapy in adults with HIV/Aids treated at a reference service. Rev min enferm. 2018 [cited 2021 Dec 04]; 22:e-1127. DOI: http://www.dx.doi.org/10.5935/1415-2762.20180050 .
20. Brunetta BF, Miguel RL, Raitz A, Quadros RMQ. Adherence of HIV-infected individuals to antiretroviral therapy in a municipality in southern Brazil: a challenge for health professionals. Clin biomed res. 2019 [cited 2021 Dec 04]; 39(2):140-3. DOI: https://doi.org/10.4322/2357-9730.86243.
21. Cabral JR, Moraes DCA, Cabral LR, Corrêa CA, Oliveira ECS, Oliveira RC. Adherence to antiretroviral therapy and the association in the use of alcohol and psychoactive substances. Enferm glob. 2018 [cited 2021 Dec 22]; 17(52):25-35. Available from: https://scielo.isciii.es/pdf/eg/v17n52/en_1695-6141-eg-17-52-1.pdf.
22. Mello CJFA, Amaral JCS, Costa MS, Cavalcante MNM, Rêgo NMS, Silva LMR, *et al*. Antiretroviral Therapy: main causes of abandonment in the state of Amapá. REAS/EJCH. 2020 [cited 2021 Dec 02]; 12(8):e3423. DOI: https://doi.org/10.25248/reas.e3423.2020.
23. Setianingrum F, Rautemaa-Richardson R, Denning DW. Pulmonary cryptococcosis: a review of pathobiology and clinical aspects. Med Mycol. 2019 [cited 2021 Dec 15]; 57(2):133–50. DOI: https://doi.org/10.1093/mmy/myy086.
24. Souza HC, Passos XS, Camplesi Júnior M., Silva AMTC., Oliveira AKS, Marques LOR, et al. Counting of TCD4+ lymphocyte and viral load in HIV+ patients in reference laboratory. Rev bras mil cienc. 2020 [cited 2021 Dec 17]; 6(15):73-8. DOI: https://doi.org/10.36414/rbmc.v6i15.50.
25. Bermúdez XPD. Trajetórias e horizontes da epidemia de aids no Brasil. Relatório 30 anos de SUS, que SUS para 2030? Universidade de Brasília e Organização Pan-Americana da Saúde- Organização Mundial da Saúde no Brasil. 2018. [cited 2021 Dec 23]; p. 188-202. Available from: https://apsredes.org/pdf/sus-30-anos/09.pdf.
26. Chamberlin S, Mphande M, Phiri K., Kalande P, Dovel K. How HIV clients find their way back to the ART clinic: a qualitative study of disengagement and re-engagement with HIV care in Malawi. AIDS behave. 2022 [cited 2021 Dec 23]; 26(3):674-85. DOI: https://doi.org/10.1007/s10461-021-03427-1.

27. MacCarthy S, Saya U, Samba C, Birungi J, Okoboi S, Linnemayr S. “How am I going to live?”: exploring barriers to ART adherence among adolescents and young adults living with HIV in Uganda. BMC Public Health. 2018 [cited 2022 Dec 20]; 18:1158. DOI: https://doi.org/10.1186/s12889-018-6048-7.
28. Costa MAR, Teston EF, Spigolon DN, Dias LO, Soares CC. Qualidade de Vida sob a Ótica de Portadores de Hiv/Aids: Perspectivas Futuras nas Práticas Educativas. Rev Fund Care. 2019 [cited 2021 Nov 26]; 11(5):1326-32. DOI: http://dx.doi.org/10.9789/2175-5361.2019.v11i5.1326-1332.
29. Van der Kop ML, Muhula S, Nagide PI, Thabane L, Gelmon L, Awiti PO. Effect of an interactive text-messaging service on patient retention during the first year of HIV care in Kenya (WelTel Retain): an open-label, randomised parallel-group study. Lancet Public Health. 2018 [cited 2022 Dec 19]; 3: e143–52. DOI: http://dx.doi.org/10.1016/S2468-2667(17)30239-6.
30. Twimukye A, Naggirinya AB, Parkes-Ratanshi R, Kasirye R, Kiragga A, Castelnuovo B, et al. Acceptability of a Mobile Phone Support Tool (Call for Life Uganda) for promoting adherence to antiretroviral therapy among young adults in a randomized controlled trial: exploratory qualitative study. JMIR Mhealth Uhealth. 2021[cited 2021 Dec 15]; 9(6):e17418. DOI: https://doi.org/10.2196/17418.
31. Lima ICV, Galvão MTG, Pedrosa SC, Farias OO, Silva CAC, Cunha GH. Instant messaging application for the care of people living with HIV/aids. Rev bras enferm. 2019 [cited 2021 Dec 10]; 72(5):1161-6. DOI: http://dx.doi.org/10.1590/0034-7167-2017-0698.
32. Umeokonkwo CD, Onoka CA, Agu PA, Ossai EM, Balogun MS, Ogbonnaya LU. Retention in care and adherence to HIV and AIDS treatment in Anambra State Nigeria. BMC infect dis. 2019 [cited 2021 Dec 12]; 19:654. DOI: https://doi.org/10.1186/s12879-019-4293-8.
33. Fernandes LTB, Nóbrega VM, Sales MLXF, Reichert APS, Moura FM, Collet N. Supported self-care actions for children and teenagers with chronic diseases. Texto - contexto enferm. 2019 [cited 2021 Dec 21]; 28:e20180325. DOI: https://doi.org/10.1590/1980-265X-TCE-2018-0325.
34. Silva SO, Machado LM, Schimith MD, Silva LMC, Silveira VN, Bastos AC. Nursing consultation for people with diabetes mellitus: experience with an active methodology. Rev bras enferm. 2018 [cited 2021 Dec 11]; 71(6):3103-8. DOI: http://dx.doi.org/10.1590/0034-7167-2017-061.
35. Rodrigues M, Maksud I. Abandonmet of treatment: therapeutic itineraries of HIV/Aids patients. Saúde debate. 2017 [cited 2021 Nov 28]; 41(113):526-38. DOI: https://doi.org/10.1590/0103-1104201711314.
36. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Secretaria de Vigilância em Saúde. Guia Política Nacional de Atenção Básica – Módulo 1: Integração Atenção Básica e Vigilância em Saúde [recurso eletrônico] Brasília. 2018 [cited 2021 Dec 11]. Available from: https://bvsms.saude.gov.br/bvs/publicacoes/guia_politica_nacional_atencao_basica_integracao_atencao_basica_vigilancia_saude_modulo 1.pdf.
37. Silva Dos Santos DS, Ferreira Bispo TC, da Silva Meneses EJ. Mulheres encarceradas com soropositividade para HIV: percepção sobre a adesão ao tratamento. Rev brasil saude Fund. 2017 [cited 2021 Dec 20]; 1(1):22. Available from: https://seer-adventista.com.br/ojs3/index.php/RBSF/article/view/883.
38. Lopes LM, Andrade RLP, Arakawa T, Magnabosco GT, Nemes MIB, Ruffino Netto A, et al. Vulnerability factors associated with HIV/AIDS hospitalizations: a case-control study. Rev bras enferm. 2020 [cited 2022 Jan 11]; 73(3):e20180979. DOI: http://dx.doi.org/10.1590/0034-7167-2018-0979.