Health education for people living with HIV in partial virologic suppression: convergent care research

Educação em saúde para pessoas vivendo com HIV em supressão virológica parcial: pesquisa convergente assistencial

Educación sanitaria para personas que viven con VIH en supresión virológica parcial: investigación convergente asistencial

Abstract

Objective: To analyze the process of implementing health education for people living with HIV in partial viral suppression with a view to rescuing adherence to antiretroviral therapy. Methods: Convergent Care Research carried out with 13 HIV-infected people, with partial viral suppression. Through the stages of conception, instrumentation, scrutiny and analysis, the reasons for treatment failures were identified, health education was implemented and the process was analyzed with interviews and content analysis. The educational process took place with the support of educational technology: Educational Material on HIV (INPI: BR 10 2020 003765 0). Results: Treatment failures were due to the following reasons: side effects, prejudice, family problems, difficulty in accessing the health service and forgetfulness. Three categories emerged from the speeches after the intervention: 1- Awakening to the importance of the correct use of antiretroviral therapy; 2- Feelings arising from the educational process; 3- Knowledge and overcoming social stigmas. Conclusion: Educational technology, added to the choice of participatory research as a method, provided learning for all involved, making it possible to perceive the importance of strengthening the teaching-service bond, the use of dialogue in the context of collectivity and investigative convergence for care practice.

Descriptors: Nursing; HIV; Acquired Immunodeficiency Syndrome; Cooperation and Adherence to Treatment; Health education.

Whats is already known on this?
The use of educational technologies promotes positive experiences for PLHIV, contribute to improving the bond between professionals and PLHIV and provide access to information and reflections about the disease.

What this study adds?
The results of the study highlight the positive impact of educational technology in raising awareness, adherence to treatment and coping with emotional and social challenges related to HIV. This can have important consequences for improving the quality of life and care provided to PLHIV.
INTRODUCTION

Four decades after the discovery of the Human Immunodeficiency Virus (HIV), global data account for more than 80 million people infected and 32 million deaths due to AIDS (Acquired Immunodeficiency Syndrome).\(^1\)

Currently, HIV infection is classified as a chronic condition, which requires control by the continuous use of Antiretroviral Therapy (ART). It acts by preventing virus replication within CD4+ Lymphocytes and, consequently, their destruction by the effects of viral replication. The correct and continuous use of ART promotes viral suppression (decrease in HIV viral load to levels below 50 copies per cubic millimeter of blood), also called undetectable viral load and immune reconstitution.\(^2\)

In contrast, non-adherence or low adherence to ART maintains HIV viral replication, which increases the risks of transmission and may promote the selection of drug-resistant viral strains, favoring progression to AIDS and impairing the quality of life of people living with HIV (PLHIV).\(^2\) Another consequence of low adherence to ART is partial viral suppression, defined by detectable viral load in the blood and decreased CD4+ Lymphocyte count, after initiation of ART.\(^3\)

In view of this scenario, the Pan American Health Organization (PAHO) proposed a set of measures to improve care for PLHIV,\(^4\) which include early diagnosis, user attachment and retention in specialized health services, the provision of ART and the achievement of undetectable viral load. To achieve these goals, the health team can implement health education strategies to support the users during treatment.\(^2\)

Educational processes can promote the quality of life of PLHIV, and the health team, especially nurses, should be a facilitator of this trajectory, since their role as educators is specified from the legal bases of their initial training, in the National Curriculum Guidelines (NCGs),\(^5\) to their Law on the Professional Practice of Nursing.\(^6\)

However, even if nurses are competent educators in the HIV universe, it is necessary to use didactic support resources, since educational technologies facilitate the relationship between professionals and PLHIV, favor access to information together with emotional support and enable reflections to live with the disease, resulting in positive experiences in its elaboration process.\(^7\)
Considering the need to support the care of PLHIV from the perspective of health education, the guiding question of this research arose: how to implement an educational process for PLHIV in partial virological suppression with a view to rescuing adherence to ART?

From these slogans and in order to support health education actions for PLHIV, a wide search was carried out in the international and national patent bases (National Institute of Intellectual Property – INPI), however no health education methodology for PLHIV was found, except for the proposal of a game called "AIDS: the epidemic board game" (Registration - US5228860), proposed in 1993, consisting of a board with the designations for "virus", "Hospital", "Physician's Office" etc. around a central area of the "cemetery" and a timeline of mortality. Pieces that are “infected” with AIDS in the course of the game “expire”.

This laconic scenario about educational technologies on HIV motivated the elaboration of the "Educational Material on HIV" (patent filed with the National Institute of Industrial Property – Registration: BR 10 2020 003765 0) by a professor from the Nursing Department of the State University of Londrina (SUL). This technology was validated by expert professionals. (8)

Given the above, this study aimed to analyze the process of implementing health education to PLHIV in partial viral suppression with a view to rescuing adherence to ART.

METHODS

Qualitative research based on Convergent Care Research (CCR), whose core is to find problems that emerge from the care field and seek, in the scientific method, the resolution for such, thus converging care and research. (9) The coherence in the choice of CCR for this study is based on the topics described in box 1.

**Box 1. Justification for the choice of CCR as a method. Londrina, PR, Brazil.**

<table>
<thead>
<tr>
<th>CCR Characteristics</th>
<th>Application in this Study</th>
</tr>
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<tbody>
<tr>
<td>a) The theme to be researched emerges from the development of care</td>
<td>Throughout the clinical practices, during the direct supervision of the students of the undergraduate nursing course at a public university in Paraná, Brazil, one of the authors, nurse and professor, identified that some PLHIV attended in the specialty service presented partial virological suppression.</td>
</tr>
<tr>
<td>b) CCR is committed to improving the context in which it develops</td>
<td>Based on the problems identified in the care reality, situational diagnosis and educational process, it was possible to elucidate doubts about PLHIV, informing them about the correct adherence to ART.</td>
</tr>
<tr>
<td>c) The researcher assumes the role of care provider</td>
<td>During the research, the authors accompanied the students in the nursing consultation and health education, competencies inherent to the professional practice of nurses.</td>
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<tr>
<td>d) The research must be carried out where the social relations proposed by the same occur</td>
<td>The investigation took place in the physical space of the health service, of construction of the teaching-learning and care process, during the clinical practices of the Communicable Diseases module, which makes up the curricular matrix of the undergraduate nursing program.</td>
</tr>
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</table>

Source: Adapted from Trentini, Paim e Silva, 2014.

The study scenario was a Specialized Care Service (SCS) in the North of the State of Paraná, Brazil, linked to the Municipal Program for the Control of Sexually Transmitted Infections (STI)/HIV/AIDS.

All 28 patients in partial virologic suppression who were in care during the clinical practices of the undergraduate course from October 2021 to May 2022 were invited to participate in the research, and 13 accepted and met the following inclusion criteria: being over 18 years of age; being linked to the service and being in partial virologic suppression.

This convenience sample presented sufficient density to achieve the proposed objectives, since the experience and its testimonies favored the identification of constructs about the phenomenon and its relationships. To this end, the operationalization of this study took place according to the stages proposed by the CCR: (9) conception, instrumentation, scrutiny and analysis.

In the design stage, the phenomena to be studied were chosen to improve the assistance provided, identifying the need to implement the educational process for PLHIV in partial virological suppression. During the instrumentation, the methodological definition occurred and a situational diagnosis was made that identified the reasons for adherence failures and some empirical perceptions of the patients that, a posteriori, supported the educational process.
Scrutiny is the stage in which a careful investigation is developed to improve care practice and relevant scientific knowledge. Here was the educational process itself. The patient who attended the consultation had his updated viral load tests (test performed in the last 12 months) analyzed to detect partial virologic suppression and was invited to participate individually in health education, lasting approximately 60 minutes in a private office. The “Educational Material on HIV” was used, an illustrative method (available at: https://youtu.be/caOEnCbnisE) that provides dynamic and interactive guidance on the natural cycle of virus infection, the development of AIDS, the action of ART, the achievement of viral suppression through continuous adherence to treatment, as well as the development of viral resistance due to non-adherence to treatment. It consists of pieces made of plastic material that illustrate the bloodstream, CD4+ lymphocytes, HIV sensitive and resistant to ART, pills that represent drug therapy for HIV and its antiretroviral action. Immediately after the educational process, patients were informed about the interview method and signed the Informed Consent Form (ICF). Subsequently, the semi-structured interview with each participant was conducted by two researchers who authored this study, with audio recording, guided by the following questions: 1) Tell me in detail how it was for you to participate in this educational process; 2) After this educational activity, do you feel motivated to reach an undetectable viral load? Why? Explain; 3) Was the way we carried out this education process useful to clarify your doubts? Why? Tell us more about it; 4) Would you recommend this education process to people who, like you, are living with HIV? Justify your answer. Although the dynamics of the study scenario did not allow time for the participants to process and reflect on the information obtained in the educational process before being submitted to the interview, we sought to mitigate this issue by providing a welcoming environment and a careful approach during the questions, aiming to obtain significant insights from the participants even in a short period of time. The fourth stage was the analysis, which provides the convergence of research to the care field, strengthened by the discussion of data. Thus, after literal transcription of the interviews, the Content Analysis was carried out. To ensure the rigor recommended by the analysis technique, in the pre-analysis phase, the speeches were transcribed literally through listening to the audio and manual typing in Microsoft Word by the main researcher, with a later conference by another author of this research. Each interviewee received identification from I1 to I13 (interviewee 1 to interviewee 13), constituting the textual corpus. Subsequently, the ‘floating reading’ was carried out, which corresponds to repeated readings to appropriate the corpus as a whole, without looking for any specific discursive element. Only after this stage were the clippings of the significant speeches chosen to respond to the objective of the study. These clippings, which totaled 28 in this investigation, are called ‘indexes’, correspond to themes frequently repeated in the participants’ speeches and have literal wording to that of the transcription of the interviews. When the indexes were listed, the exploration of the material began, coding each of them in order to transform them into nuclei of understanding (nuclei of meaning). These nuclei are called ‘registration units’, which have been grouped by similarity to form the categories. Finally, the results were treated, during which the findings were interpreted, supported by literature and exemplifications using coded speeches expressed by the participants. The study followed the recommendations established by Resolution 466, of December 12, 2012, and was approved by the Research Ethics Committee of the study institution, under opinion 3,980,965 of April 20, 2020 and CAAE (Certificate of Presentation of Ethical Appreciation) number 30299820.3.0000.5231. It followed the consolidated criteria for reporting qualitative research Consolidated Criteria for Reporting Qualitative Research (COREQ). RESULTS Of the 13 participants, five were men and eight were women, ranging in age from 23 to 71 years. The time of diagnosis was between six and 27 years and the use of ART ranged between seven and 27 years. The viral load identified in the sample ranged from 45 copies/ml to 67,930 copies/ml.
Situational Diagnosis

During the situational diagnosis, carried out in the approach to the participant, it was noted that the main factor that led to PLHIV partial virologic suppression was the failure to adhere to ART, due to reasons related to the side effects of the drugs, prejudice arising from interpersonal relationships, family problems that reflected in the lack of support regarding the acceptance of the diagnosis and treatment, difficulties in accessing the health service and forgetting the doses of the drugs. These reasons and their consequences are shown in figure 1.

**Figure 1.** Reasons identified for failure to adhere to treatment for HIV infection and its ramifications. Londrina, PR, Brazil, 2021-2022.

Educational Process

During care, patients received didactic and interactive explanations about the pathogenesis of HIV, its action in the human organism, the different phases of the infectious cycle, and the interpretation of its results from the CD4+ Lymphocyte count and viral load tests, and the action of ART through the use of educational technology (Figure 2). This process allowed the patients to identify in their viral load tests the results that proved partial virologic suppression.
Figure 2. Images of the use of educational technology on HIV in the educational process of People Living with HIV in partial virological suppression. Londrina, PR, Brazil, 2021-2022.

Legend: A - HIV replication cycle; B - Increase in viral load and reduction of CD4+ Lymphocytes; C - Action of antiretrovirals and presentation of undetectable levels of HIV; D - Viral replication and selection of resistant strains due to failure in drug adherence.

Perception of PLHIV after the educational process

The content analysis of the interviewees' statements after health education led to the emergence of three empirical categories: 1) Awakening to the importance of the correct use of ART 2) Feelings arising from the educational process and 3) Knowledge in overcoming social stigmas.

Category 1: Awakening to the importance of the correct use of ART

The first category demonstrates that the educational process brought to light the interviewees' greater understanding of the pathophysiology of HIV, as exemplified by the following excerpts:

The explanation was wonderful, because in this way it was possible to understand much better. I better understood how the disease process occurs, what happens, what does not happen. Many times I was lost, not understanding anything. I took the medication, but without knowing what was happening. (I4)

It became clearer, because we do not know our enemy well. So, in this way, it became more didactic, I could understand better. (I8)

That explanation helped make it clearer, for sure. Before that, it was difficult to get a sense. With this material, you already have a sense of what it is, because you are seeing the blood there, you are seeing what the "bug" is, what the cell is and its defense. (I6)

From the pathophysiological understanding of HIV, the participants also mentioned that the educational technology made them understand the importance of the correct use of ART in the prevention of complications in their clinical condition:

Great explanation! I will try to remember everything, because if I do not take the medication it only tends to worsen HIV. (I2)

For me, this explanation was different and I understood that the lack of use of the medication can affect my body even more, so for me, I found it very interesting [...] because as it represents the bloodstream, we already see and, using the most natural colors, we understand more. (I3)

For me, he explained a lot so that I wouldn't stop the treatment, so that I wouldn't get sick. He made it very clear to me, the drawings and the explanation were very simple and we understand. It's not the same as that medication language, it was simple and made it very clear that I have to treat myself and take care of myself, because I'm not sick yet [...] now I feel more relieved and I got calmer. (I5)
Category 2: feelings arising from the educational process

In this second category, respondents expressed positive feelings after participating in health education, such as joy and hope to continue with appropriate treatment. The following excerpts illustrate such insights:

This understanding gives more hope, [...] a feeling that it will work, the medication will work and that, really, everything will be calm. It's a change. (I4)

I understood that today I don't have a virus in my blood in a way that I can transmit it. I was happier to know that I can't transmit it, because that's the main thing: we know that we don't transmit the virus. (I5)

This knowledge already greatly improves the quality of life; it has already cheered me up a lot! (I11)

I found this explanation very interesting, as the method used, as an illustrative way, helps in the understanding and comprehension of HIV. (I3)

Category 3: knowledge in overcoming social stigmas

In this third category, the PLHIV mentioned that the educational process strengthened them to overcome taboos and prejudice, contributing positively to the understanding of the disease, life cycle and quality of life with the understanding of the importance of monitoring with ART. The following excerpts illustrate such questions:

It is an explanation that clarifies that, if you take care of yourself, you will continue to be well. You don't have the disease, you just have the virus. So, it takes away that weight of thinking you have AIDS, which is a strong word. I am HIV positive, I do not have AIDS. This process [health education] takes away that weight and it's very good because I understand more. (I5)

It clarifies for those who do not have the virus what the situation of the HIV-positive person is and that the person can live normally with HIV. (I6)

Prejudice that I experience from my family, even from my own mother, who after I use the bathroom, she cleans the entire bathroom, because she thinks I'm going to transmit the virus, I try to explain, but she doesn't understand. (I5)

My husband’s family [...] is prejudiced, but I ignore it. I end up omitting my diagnosis, because I know they are prejudiced. (I7)

Sometimes I would travel and I had to take seven pills. As there were many people close to me, I ended up not taking the medication, for fear of people's reaction. (I8)

My mother was afraid that the mosquito would sting me and end up stinging the family members who lived with me and, thus, the transmission of the HIV virus to them happened; this made me psychologically ill. (I10)

DISCUSSION

HIV patients who adhere to ART have a longer survival, improved quality of life and reduced transmission of the virus due to viral suppression. However, living with a stigmatized, chronic infectious disease is challenging, as elucidated in the situational diagnosis of this study.

The frequency of administration and dosage, forgetfulness in the use of ART, side effects, financial problems and difficulty in moving to health services are factors that directly affect adherence to treatment. (12)

However, one cannot fail to consider that low adherence to the treatment of PLHIV is also associated with the complexity of some prescribed regimens, side effects of some medications, such as gastrointestinal effects, difficulty in taking medications according to the prescribed dose and time, and insufficient knowledge about the infection and ART. (13)
In the emotional and cognitive context, some obstacles to adherence to ART identified in the literature include non-acceptance of the diagnosis, unsatisfactory relationship of the patient with the health team, family conflicts, negative beliefs about the pathology, psychiatric disorders and abuse of alcohol and other drugs. Such aspects can be added to socioeconomic factors such as low education and precarious social conditions.\(^{(13)}\)

There are multiple factors related to treatment adherence. It involves sociodemographic, clinical and behavioral aspects, and these should be considered in the development of strategies that favor adherence to ART by PLHIV. The health team must develop an approach that meets the sociocultural and subjective singularities, and in this sense, the use of educational materials can support and direct the health professional’s dialogue with PLHIV, from the diagnosis of virus infection, as well as adherence to drug therapy.\(^{(12)}\)

From this perspective, the first empirical category presented in the results revealed that the educational process based on an interactive technology favored the understanding of the benefits of ART, and consequently, stimulated the continuous use of the therapy. This is in line with related literature, which identified that, in HIV educational processes, the use of active actions and methodologies lead to a set of positive results, as well as favoring the integration of health professionals with the target audience.\(^{(14)}\)

The United Nations Educational, Scientific and Cultural Organization (UNESCO) encourages the action called Education for Global Citizenship (EGC), consisting of teaching, learning and educational technology practices with interactive, participant-centered approaches that design an assessment that supports learning,\(^{(15)}\) being consistent with what is presented in this research.

The teaching-learning process, combined with educational technologies, expands health education strategies, in addition to enabling autonomy for the learner, making the space and time of learning flexible.\(^{(16)}\)

In the second category, it was evident that the educational process provided the feeling of hope and joy to PLHIV. It is a fact that the expansion of knowledge by anyone and in any situation can provoke new feelings. In this sense, authors reflect on studies carried out in the field of neuroscience, in which it was evidenced that the link between emotional moments and cognitive construction, in its different contexts, are inseparable processes.\(^{(17)}\) In addition, it is added that the values developed as a unit between affective and cognitive processes have emotional and dynamic bases that are transformed by the conceptualization of thoughts.\(^{(18)}\)

It is noted that the statements found in the literature are consistent with the statements of the respondents, since, when experiencing the feeling of hope, they also experienced joy, which motivated them to continue using ART. It is conjectured, therefore, that the knowledge provided gave PLHIV positive feelings, despite their chronic health condition.

The less is known about a given phenomenon, the more there is a tendency to fear it, especially when dealing with illness, a comprehensive and intricate phenomenon that encompasses not only physical events, but also psychological factors, and generates social and cultural learning processes within the interactions experienced.\(^{(19)}\) Thus, health education can greatly contribute to the deconstruction of this fear, even more so when built on innovative and participatory practices.

Regarding the research presented here, the educational process also played a welcoming role and, with the clarification about HIV, the participants were optimistic, with statements that signal the strengthening of their role as protagonists of their own treatment.

The third category strengthened the idea that, from the educational process implemented, there was greater clarification to the participating PLHIV, reducing the influence of the social dogmas circumscribed to this pathology. It is undeniable that the existence of myths and taboos can hinder the dissemination of adequate information to society and that the expansion of knowledge through innovative educational technologies can be allied to the rupture of this reality.

In addition, the social stigma entrenched since the advent of HIV infection remains a hindrance to the success of treatment and haunts patients even with all the therapeutic possibilities in force. Not infrequently, the death/dying process of people with AIDS is permeated by non-acceptance of the disease, lack of adherence or misuse of ART.\(^{(20)}\)

By implication, health education is a powerful tool in this context, since knowledge is emancipatory and can contribute to breaking the bonds of prejudice established in a society. After participating in the educational process with the support of a differentiated technology, the respondents signaled to reduce
their own prejudices about HIV and mentioned the intention to adhere to treatment to achieve viral suppression and undetectable viral load.

Knowledge is the foundation for hope and strengthening of bonds, confirming that there is a need to expand the look beyond the physiological issues of the disease, understanding that PLHIV have specific issues that impact their way of relating to the world, their constructions of bonds and their quality of life.\(^\text{21}\)

PLHIV often have difficulty talking to other individuals about their diagnosis, due to the fear of being rejected and several impacts are related to this disease, such as guilt for having been infected, non-adherence to medication, disclosure of social identity, revolt and excessive consumption of alcohol.\(^\text{22}\)

The statements found in the literature endorse the participants' statements that the knowledge provided by the educational moment brings benefits and improves quality of life, as understanding the infection can empower PLHIV for self-care.

At the end of this research, we intend to outline the limitations of this study, one of which is the fact that some eligible PLHIV did not accept to participate in the interview. Although this quantity was sufficient to achieve the proposed objective, it is understood that a greater number of patients would broaden and strengthen the discussion. Another limitation to be mentioned is the generalization of the results to other populations due to the fact that data collection has been made possible only in one location, recommending its replication in other realities and with a greater time frame.

Based on the above, it is believed that this research contributed to an analysis of the need for the use of educational technology in health, to support health professionals in the process of teaching and learning about HIV/AIDS, as well as to a better understanding of PLHIV on infection, empowerment to generate self-care strategies, breaking taboos and stigmas and generating an awakening to the correct use of ART.

CONCLUSION

The educational technology used here to support health education in addition to the use of CCR provided PLHIV with contributions to overcoming the difficulties of accepting the diagnosis, sharing personal experiences and problematizing self-care strategies. The speeches denoted that participation in the educational process contributed to better coexistence with the infection, to the (re)construction of knowledge, clarification of doubts, breaking of taboos/prejudices about adherence to treatment and healthy life habits, with a view to promoting quality of life.

The use of educational technology to support health education, together with the use of CCR, has made important contributions to PLHIV. These contributions are related to overcoming the difficulties of accepting the diagnosis, sharing personal experiences and reflecting on self-care strategies. The participants' statements showed that participation in the educational process contributed to better living with HIV infection. Access to knowledge and the opportunity to clarify doubts allowed a reconstruction of knowledge about the infection. In addition, the educational process contributed to the breaking of taboos and prejudices related to adherence to treatment and the adoption of healthy lifestyle habits.

The results suggest that the use of educational technology and the CCR approach have the potential to strengthen self-care, stimulate treatment adherence, and provide a welcoming environment and exchange of experiences. Thus, the findings of this study reinforce the importance of investing in innovative and patient-centered educational approaches, using technology as an ally in the health education process for people living with HIV. These interventions can contribute to promoting quality of life and combating the stigma and prejudice associated with the disease.

CONTRIBUTIONS

Study conception or design: Souza LC, Montezeli JH, Kerbauy G. Data collection: Souza LC, Montezeli JH, Kerbauy G. Data analysis and interpretation: Souza LC, Sakai AM, Higarashi IH, Pieri FM, Montezeli JH, Kerbauy G. Writing the article or critical review: Souza LC, Sakai AM, Higarashi IH, Pieri FM, Montezeli JH, Kerbauy G. Final approval of the version to be published: Souza LC, Sakai AM, Higarashi IH, Pieri FM, Montezeli JH, Kerbauy G.

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