## EXPERIENCE REPORT

# EDUCATIONAL TECHNOLOGY FOR PROMOTING QUALITY OF LIFE OF PEOPLE LIVING WITH HIV

TECNOLOGIA EDUCATIVA PARA PROMOÇÃO DA QUALIDADE DE VIDA DE PESSOAS QUE VIVEM COM HIV

TECNOLOGÍA EDUCATIVA PARA MEJORAR LA CALIDAD DE VIDA DE LAS PERSONAS QUE VIVEN CON EL VIH

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#### **ABSTRACT**

The objective of this study was to report the experience of nursing undergraduate students in conducting health education workshops with people living with HIV. The workshops were held from a university extension project aimed at people living with HIV, held in a waiting room of a Specialized Care Service in HIV/AIDS. A total of 64 actions were held from March 2013 to December 2014, by using educational technologies such as the preparation of didactic-pedagogical materials by nursing undergraduate students. The workshops have enabled the HIV-positive individuals to overcome the difficulties of acceptance of the diagnosis, sharing personal experiences and discussion self-care strategies. Moreover, given the applicability in developing educational workshops, they were implemented in the service routine, thereby being carried out by professionals who work in it. The practices have contributed to a better living with the disease by the re-construction of knowledge about treatment adherence and healthy living habits, with a view to promoting quality of life.

Keywords: Health Education; HIV; Acquired Immunodeficiency Syndrome; Quality of Life; Nursing.

#### **RESUMO**

O objetivo deste estudo foi relatar a experiência de estudantes do curso de Enfermagem na realização de oficinas de educação em saúde com pessoas que vivem com HIV. As oficinas foram realizadas a partir de um projeto de extensão universitária voltado para as pessoas que vivem com HIV, realizado em uma sala de espera de um Serviço de Assistência Especializada em HIV/AIDS. Foram realizadas 64 oficinas no período de março de 2013 a dezembro de 2014, utilizando tecnologias educativas como a confecção de materiais didático-pedagógicos, pelos estudantes do curso de Enfermagem. As oficinas proporcionaram às pessoas soropositivas a superação das dificuldades de aceitação do diagnóstico, compartilhamento de experiências pessoais e a problematização de estratégias de autocuidado. Além disso, tendo em vista a aplicabilidade na execução das oficinas educativas, elas foram implantadas na rotina do serviço, sendo continuadas pelos profissionais que nele atuam. As práticas contribuíram para a melhor convivência com a doença pela reconstrução do conhecimento sobre a adesão ao tratamento e hábitos de vida saudáveis, com vistas à promoção da qualidade de vida.

Palavras-chave: Educação em Saúde; HIV; Síndrome da Imunodeficiência Adquirida; Qualidade de Vida; Enfermagem.

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#### RESUMEN

El objetivo de este estudio fue reportar la experiencia de los estudiantes de enfermería sobre la implementación de talleres de educación para la salud, como una tecnología educativa para promover la calidad de vida de las personas que viven con el VIH / SIDA. Los talleres se llevaron a cabo a partir de un proyecto de extensión universitaria dirigido a dichas personas, en una sala de espera de un centro de servicio especializado en VIH / SIDA. Fueron realizados 64 talleres de marzo de 2013 a diciembre 2014, utilizando tecnologías de enseñanza como la elaboración de materiales de enseñanza-aprendizaje, por los estudiantes de enfermaría. Los talleres proporcionaron a las personas VIH-positivas la posibilidad de superar las dificultades de aceptación del diagnóstico, el intercambio de experiencias personales y el cuestionamiento de estrategias de autocuidado. Además, considerando la aplicabilidad en la realización de los talleres educativos, éstos fueron implementados en la rutina de los servicios y continuados por los profesionales de tales servicios. Las prácticas contribuyeron a una aceptación mejor de la enfermedad, por medio de la construcción de conocimientos acerca de la adherencia al tratamiento y de hábitos saludables, con el fin de promover la calidad de vida.

Palabras clave: Educación en Salud; VIH; Síndrome de Inmunodeficiencia Adquirida; Calidad de Vida; Enfermería.

#### INTRODUCTION

Brazil is considered one of the first countries in the world to adopt inclusive and universal public policies in relation to the promotion, prevention and recovery of HIV / AIDS. After three decades of the epidemic, AIDS has been stable nationally, with reductions in mortality rates in all age groups and vertical transmission, in addition to early provision of antiretroviral therapy to all people living with HIV (PLHIV). It is worth noting that in the Brazilian scenario it was possible to improve the quality of life of PLHIV and increased survival of patients since the beginning of the free provision of antiretrovirals.<sup>1</sup>

The quality of life of PLHIV involves, in addition to drug therapy, social, religious and cultural aspects, which are research objects in health area. Researcher have sought, from scientific evidence, to offer comprehensive, humane and resolute care, consistent with the real needs of these people, from the infection prevention to health recovery.<sup>2</sup>

According to the World Health Organization (WHO), the quality of life is defined as: "individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".<sup>3</sup>

In this sense, health education interventions play a key role in promoting the shared construction of a reflective and critical knowledge about a specific theme from participants' experience and reports. In this perspective, the implementation of health education strategies for PLHIV, developed through technological tools, has helped to improve the welfare of these people.<sup>4</sup>

Health education, understood as a care technology, is a tool that recognizes knowledge, practices and cultural background of the people involved in the educational process. Its implementation is guided in dialogue and experience-sharing between participants and health professionals involved in order to reach consensus in the group. The educational workshop in health is one of the tools of educational technology, since from it one can promote health and quality of life by building a bond of responsibility and affection between the health team and participants.<sup>5</sup>

In this perspective, it is extremely important to invest in workshops aimed at disseminating information about safe sexual behaviors, adherence to treatment, adoption of a healthy lifestyle, the importance of performing tests and attending medical appointments with health professionals periodically in order to prevent injuries.

In face of the commitment of the Federal University of Pernambuco (UFPE) with people living with HIV treated at its hospital, it was realized the need to develop an extension project able to promote better quality of life for these people, with the realization of health education workshops with educational technologies, enabling greater link between user and the service.

In this sense, the health education strategy from the university extension, besides contributing to improving the population's quality of life, seeks to operate in the training of students as citizens, because sharing knowledge enables awakening the sense of social responsibility, contributing to the training of professionals committed to the community and disseminators of scientific knowledge. Moreover, the inclusion of students in the work with the community favors constant revitalization of the teaching-learning process, transforming undergraduate students in professionals acting in a humane way in the process of care.<sup>6</sup>

Supported in the constructs of Paulo Freire, among them autonomy, freedom, dialogue and questioning, educational practices should be drawn from dialogic, participatory and emotional relationships in building a critical knowledge on human rights. Thus, this emphasizes the need to approach health professionals with the reality experienced by their clients, so that they can achieve positive results during the educational activity.<sup>7</sup>

So, authors intended to carry out health education workshops in a Specialized Care Service (SAE) in HIV / AIDS, in order to contribute to the learning of the staff working in the service and especially to inclusion of people with positive diagnosis for HIV in self-care interventions, aiming to provide means and knowledge to enable them to create, recreate and transform their reality, with a view to improving their quality of life.<sup>6</sup>

In this perspective, and also considering the improvement in academic education of future nurses, the aim of this study was to report the experience of nursing course students in conducting health education workshops for people with HIV.

#### **EXPERIENCE DESCRIPTION**

This is an experience report arising from the extension project entitled "Health Education Actions in promoting quality of life of patients with HIV / AIDS", aiming at the realization of educational workshops to adult users of SAE in HIV / AIDS in a waiting room of the Hospital das Clinicas, UFPE, located in Recife, Pernambuco. That service provides assistance only to adult users.

The workshops were developed by extension students who formed a group composed of two masters in Nursing, 10 undergraduate students in Nursing and the multi-disciplinary team of the service (nurse, social worker, psychologist and pharmacist). They were conducted weekly on Mondays, from 1 p.m. to 3 p.m., from March 2013 to December 2014, with an average of 12 participants per workshop. Monday was chosen because it is the day the multidisciplinary team of that service had more availability to participate in the workshops. In total, the project included 462 PVHIV.

Initially, the extension students discussed possible issues that would be addressed during the health education workshops. For this, the experience of the team and the need of users assisted in the service were taken into consideration. That moment was very important, since it evidenced the need to develop educational practices to integrate users who shared the same diagnosis and enabled the establishment of the teaching-service relationship.

Users were integrated into the group by spontaneous demand, that is, people with HIV in the waiting room were included and agreed to participate after the invitation and providing information about the purpose and nature of the extension action.

Authors developed 64 health education workshops with diverse themes about quality of life. The structuring of the activities was guided and adapted according to the Multiplier Manual (Manual do Multiplicador, from the Brazilian Ministry of Health).8

In order to arouse critical thinking and reflection on the role of each participant in the context of promoting quality of life, different strategies were selected for the development of the topics, including: interaction and communication games; questions and answers; relaxation; body movement; dialogued exhibitions, using different audiovisual resources to provide material to the discussions; manual activities of art therapy and verbal report among participants in order to achieve interaction and exchange of experiences and knowledge.

The workshops were divided into eight categories to provide better planning of each, and were subsequently catego-

rized into themes and developed from the above mentioned strategies. The categories were: preparation of teaching-learning material, art therapy activities, creating drawings, HIV montage, adherence to ART, phrase montage, clarifying questions and physical activity.

To better conducting workshops, at least three nursing students participated, distributed and organized as follows: two mediators, responsible for the direction and development of thematic content HIV / AIDS and for the motivation and interaction among participants in the proposed debates; and the observer, responsible for recording the lines and emphasizing the ideas contained therein, as well as for monitoring the conduction of the group.

The record of the workshops was held in field diaries, aimed at guiding discussions between the extension students and thus carrying out continuous assessment of activities.

## EXPERIENCE REPORT AND DISCUSSION

Workshops were held with people living with HIV who were in the waiting room of an SAE. The purpose of the workshops was to promote quality of life. Extension students discussed the possible topics to be addressed during the workshops, including the virus mechanism of action, adverse effects of antiretroviral drugs, healthy eating and their drug interaction, rights and duties of PLWHA and manual activities.

The involvement of people living with HIV in the workshops was obtained gradually. In the beginning of each workshop it was held an individual presentation of both the extension researchers and users attended at SAE, through the use of a badge in which each participant wrote their names, ensuring their identification throughout the workshop. In addition to identifying through the badge, each participant performed a short presentation on what they liked to do, family ties and experiences related to the disease.

Thus, each speech expressed by the participants allowed that health professionals of the service - social worker and pharmacist - performed the registration of relevant information about what people know, do and build to deal with the disease, diagnosis time and treatment, history of abandonment to antiretroviral therapy (ART) and their life experiences. This information was essential so that the aforementioned professionals could identify patients who were making irregular use of ART. Thus, individual consultations with the multidisciplinary team of the service were scheduled to promote clarification and contribute to a quality treatment adherence.

The construction of the health education workshops was based on the theoretical work of Paulo Freire, whose methodology is centered on dynamic and dialectical knowledge, faced

to universal ethics, in a reflection that values autonomy, critical thinking, culture, empirical knowledge and questions.<sup>9</sup>

In order to establish integrated care, the workshops also sought to provide to group participants the dissemination of information on HIV, respecting differences and stablishing care for life. To this end, the development of health education strategies was necessary, which have been classified into categories that are described below:

- category 1: preparation of teaching-learning material. The developed workshops used as strategies the audiovisual resource and the dialogued exposure by creating posters and albums addressing the following health topics: healthy eating, side effects of ART, ways to combat high cholesterol, diabetes prevention and arterial hypertension. To help in the development of this resources, it was held cutting and collage workshops with pictures and information about the topics. They were drawn from this category and provided the confection of teaching-learning materials by the users themselves, with the help of extension researchers. Finally, it was held discussion on the built material. It was created a flipchart with the food pyramid and advices on the health food, which was subsequently fixed in the unit as a source of information for other users.
- category 2: art therapy activities. To this category, it was adopted the strategy of manual activities of art therapy, interaction and communication. The themes used in these workshops were "painting on canvas"; "what do I wish for next year?"; and "building the frame." The workshops were held by painting on canvas, where participants expressed their feelings, and drawing up a picture frame with the use of laminated tape, crepe paper and colored glue. At the end of each year, it was held up a collective painting in which a single screen was painted by all users with the outlook for the year to come. They wanted a year full of health, love, affection, end of prejudice against HIV and prosperity.
- category 3: creating drawings. For the development of workshops, authors used the strategy of dialogued exhibitions in order to obtain group interaction from the drawings created by users. The workshop was entitled "Living without fear of being happy" and for its development they used sheets of paper, pencils, colored pens, paint and brush. With this, users created drawings that expressed images of moments, people and places that let them happy on a poster with the theme of the workshop. They drew, among other things, the birth of a nephew, a beach representing a place of peace, being accepted in a university and the family.
- category 4: montage of HIV. For the workshops, it was used modeling clay to confection of HIV as a strategy to promote verbal report among participants in order to achieve interaction and exchange of knowledge. The

- workshop was called "Fabricating the HIV". This workshop revealed the meaning of HIV for each participant. They said the virus resembled a bedbug, a poisonous snake, something bad, intelligent and indestructible, a fish with a long tail, stating the speed of the virus as the multiplication. Finally, extension researchers showed the picture of HIV obtained from microscopic examination.
- category 5: adherence to ART. The workshops were developed from the strategy of dialogued exhibitions and exchange of knowledge and experiences. For this reason, the workshop was entitled "What should I do to get a regular adherence to ART?". It was clarified to people living with HIV that adherence to ART can reduce the chance of HIV transmission, control viral replication, improve the quality of life and immune status, thus preventing the occurrence of infections opportunists. In addition, it was discussed that an adequate adherence to ART is composed of three acts: the daily dose of medication, attending medical appointments with health professionals and conducting tests.
- category 6: forming the phrase. In this category, the workshops were entitled to "unscrambling words." For this purpose, researchers used the strategy of reflection, interaction and exchange of experiences and knowledge. In these workshops, it was given the following statement to users "HIV: united by hope", whose words were scrambled. After unscrambling it, there was discussion of the meaning of the sentence for each participant, and the importance of solidarity was highlighted.
- category 7: clarification of doubts. The workshops were developed from questions and answers, all focused on the theme "no more doubts". Authors used balloons with questions and answers related to HIV transmission, ways to prevent opportunistic infections, the veracity of condom use in people who share the same diagnosis, rights and duties of people living with HIV, among others. Finally, it was held discussion on what users had learned.
- category 8: physical activity. The workshops were held from three themes: "stretching"; "dancing with balloons"; and "twisting the body" and developed to promote interaction, relaxation, body movement and teamwork. In these workshops, the group performed stretching and dance exercises. On the theme "dancing with balloons," users danced a song in pairs, joined by a balloon in their back. They could not let it fall on the ground. Thus, it was possible to perceive the group interaction from mutual work, and relaxation at the time of waiting an appointment.

Each dynamic contributed to the effectiveness of care provided to PLHIV, especially in the promotion of quality of life. It was provided the interaction in the workshops between

extension researchers and users through dialogue. At the end of each workshop, it was evaluated the performance and learning of each participant. The implementation of activities was observed and, finally, it was held a discussion on what each user had learned from the workshop.

Coupled with the Paulo Freire precepts, health education is understood as an enabling technique for the collective construction of knowledge and practices. From this perspective, health professionals need to establish with their patients a relationship based in therapeutic listening, respect and appreciation of experiences, life stories and world view.<sup>10</sup>

Thus, when carrying out health education interventions to PLHIV, nurses can play an important role in the motivation to cope with the side problems of the diagnosis. Such problems are evidenced mainly by social and family isolation, insecurity and fear of death. Thus, the focus is directed to the reduction of sexual risk behaviors, adherence to treatment and healthy lifestyle.

Through interventions conducted in the workshops, it was possible to understand the real needs of PLHIV, which include coping with it and the difficulties of accepting the diagnosis. It was identified also that prejudice has negative consequences on the daily life of individuals, generating significant losses in their quality of life.

It is worth mentioning the need of ongoing programs in SAEs, and especially in primary health care services, through educational technologies that seek to control the HIV / AIDS, deconstructing stigmas surrounding the disease, building strategies to improve adherence to treatment, rehabilitation of people living with HIV in society and in the formal labor market and the disclosure of diagnosis to third parties aiming at psychological support.<sup>12</sup>

### **CONCLUSION**

This report revealed that health education workshops in groups for people living with HIV were able to promote exchange of popular and scientific knowledge, and allowed the establishment of dialogue centered on the perpetuation of information and coping with the disease. It contributes to the reconstruction of knowledge, more adherence to treatment and the need for healthy behaviors and lifestyle habits in order to improve the quality of life.

The study provided significant learning experience for everyone involved and, through the insertion of nursing students, it was possible to realize the importance of strengthening the link between teaching and service and the use of dialogue in the community context. This favors the training of a professional with a holistic view of care to actively act on autonomy and effective participation of people in the construction of self-care.

With the development of health education workshops, it could be seen that participants became highly motivated to attend the health service in the days of activities. It is noteworthy that the main objective, of sensitizing the group for the promotion of quality of life in a joint effort, was possible due to the commitment and responsibility of the participants.

It was also observed more interaction between professionals and clients and low percentage of absenteeism to treatment. This can be justified because the developed workshops have provided more access of PLHIV to information with a view to motivate changes in attitudes in favor of their quality of life.

Thus, it is necessary to introduce educational technology workshops for promoting health and quality of life of PLHIV in services that assist people living with HIV. The aim is to provide physical and mental well-being, as well as explanations about the disease, treatment and possible health problems, and provide actions that can contribute to cope with HIV.

Finally, due to the positive results achieved through the implementation of educational workshops, the workshops were implemented in the routine of the service mentioned by the professionals working there.

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