PARTICIPATIVE DEVELOPMENT OF EDUCATIONAL TECHNOLOGY IN THE HIV/AIDS CONTEXT

DESENVOLVIMENTO PARTICIPATIVO DE TECNOLOGIA EDUCACIONAL EM CONTEXTO HIV/AIDS

DESARROLLO PARTICIPATIVO DE TECNOLOGÍA EDUCATIVA EN EL CONTEXTO VIH/SIDA

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ABSTRACT

Introduction: HIV represents a continuous and unstable worldwide phenomenon, with different forms of occurrence, depending on individual and collective behavioral determinants. AIDS stands out among infectious diseases, due to the amplitude and extent of damage caused, in addition to the high mortality. The individual living with the disease has a great impact on their lives, in the biological, personal and social spheres, leading to changes that require daily management and readaptation. Thus, in the health educational work process with these individuals, there is the possibility of building and spreading knowledge and life health practices. **Objective:** to build with health professionals an educational technology to mediate the health education process in the HIV/AIDS context. **Method:** a qualitative research in which data collection used the focus group technique, with use of a guide script composed of questions related to the presentation and content of the technology. Eight health professionals attending individuals living with HIV/AIDS in a reference unit in *Belém-Pará* participated. Data were subjected to thematic analysis. **Results:** the technology developed was a booklet entitled "Tips for Living Well". The themes that emerged concern the forms of transmission, diagnostic tests, monitoring, personal, environmental and food hygiene, and healthy eating. **Conclusion:** educational technology was built, in its form and content, with health professionals. It emerged from their daily practices and showed potential use in health services to mediate the HIV/AIDS health education work process.
Keywords: HIV; Nursing; Health Education; Educational Technology.

RESUMO

Introdução: o HIV representa fenômeno mundial contínuo e instável, com diferentes formas de ocorrência, dependendo de determinantes comportamentais individuais e coletivos. A AIDS destaca-se entre as doenças infecciosas, pela amplitude e extensão dos danos causados, além da alta mortalidade. A pessoa que vive com a doença sofre grande impacto em sua vida, nos âmbitos biológico, pessoal e social, levando a alterações que requerem manejo e readaptação no cotidiano. Assim, no processo de trabalho de educação em saúde com essas pessoas tem-se a possibilidade de construção e disseminação de conhecimentos e práticas saudáveis de vida. Objetivo: construir com os profissionais de saúde uma tecnologia educacional para mediar o processo de educação em saúde no contexto HIV/AIDS. Método: pesquisa qualitativa em cuja coleta de dados utilizou-se a técnica de grupo focal com uso de roteiro guia composto de perguntas relacionadas à apresentação e ao conteúdo da tecnologia. Participaram oito profissionais de saúde que atendem pessoas convivendo com HIV/AIDS em uma unidade de referência em Belém-Pará. Os dados foram submetidos à análise temática. Resultados: a tecnologia desenvolvida foi do tipo cartilha intitulada "Dicas para viver bem". Os temas que emergiram dizem respeito às formas de transmissão, exames para diagnóstico, acompanhamento, higiene pessoal, do ambiente e dos alimentos e alimentação saudável. Conclusão: a tecnologia educacional foi construída, em sua forma e conteúdo, com os profissionais de saúde. Emergiu de suas práticas cotidianas e mostrou-se com potencial de utilização nos serviços de saúde para mediar o processo de trabalho em educação em saúde sobre HIV/AIDS.
Palavras-chave: HIV; Enfermagem; Educação em Saúde; Tecnologia Educacional.

RESUMEN

Introducción: el VIH representa un fenómeno mundial continuo e inestable, con diferentes formas de incidencia, dependiendo de los determinantes conductuales individuales y colectivos. El SIDA se destaca entre las enfermedades infecciosas por la amplitud y alcance del daño causado, además de la alta mortalidad. La persona enferma sufre un gran impacto en su vida, en las esferas biológica, personal y social, lo que lleva a cambios que requieren manejo y readaptación cotidianos. Por lo tanto, en el proceso de trabajo de educación sanitaria con estas personas, existe la posibilidad de construir y difundir conocimientos y prácticas de vida saludable. Objetivo: construir con profesionales de la salud una tecnología educativa para mediar el proceso de educación sanitaria en el contexto del VIH/SIDA. Método: investigación cualitativa en la que la recogida de datos utilizó la técnica de grupos focales mediante un guión compuesto por preguntas relacionadas con la presentación y el contenido de la tecnología. Participaron ocho profesionales de la salud que atienden a personas que viven con el VIH/SIDA en una unidad de referencia de Belém-Pará. Los datos fueron sometidos a análisis temáticos. Resultados: la tecnología desarrollada fue del tipo de folleto titulado "Consejos para vivir bien". Los temas que surgieron se refieren a las formas de transmisión, pruebas de diagnóstico, monitoreo, higiene personal, medio ambiente y alimentos y alimentación saludable. Conclusión: la tecnología educativa se construyó, en su forma y contenido, con los profesionales de la salud. Surgió de sus prácticas diarias y mostró uso potencial en los servicios de salud para mediar el proceso de trabajo en educación de salud sobre VIH/SIDA.

Palabras clave: VIH; Enfermería; Educación en Salud; Tecnología Educacional.

INTRODUCTION

The Human Immunodeficiency Virus (HIV) infection became known worldwide in the early 1980s and represents a public health problem because of its pandemic character. It is a chronic disease that causes progressive immune deficit due to low CD4 lymphocyte levels. The lower these levels are, the higher the risk of the individual to develop complications.[1]

This infection represents a continuous and unstable worldwide phenomenon, with different forms of occurrence, depending on individual and collective behavioral determinants. AIDS has its most advanced clinical manifestations and stands out among emerging infectious diseases, due to the great amplitude and extent of damage caused, in addition to the high mortality.

With the infection expansion, the search for information and guidance strategies directed to people living with HIV/AIDS and their families, by the professionals who accompany them in the health units' daily routine, is essential.

The individuals living with HIV/AIDS suffer a great impact on their lives in the biological, personal and social spheres, which leads to changes that require management and readaptation in daily activities.[2] In the health education work process there is the possibility of building and disseminating knowledge and healthy life practices. Due to its chronicity and transmissibility, it is required from health professionals to collaborate in coping with problems, not only health but those related to other aspects of quality of life, based on the social and family scenario of these individuals.[3]

Educational technologies mediate health education actions and facilitate the relationship between professionals and individuals living with HIV/AIDS, favoring access to information together with emotional support and risk assessment and enabling reflections on values, attitudes, behaviors, and strategies to live with the disease. The technologies are devices that allow reflections and result from the daily experiences of those involved in their elaboration process.[4]

In medical work, we can define three types of technologies that indicate different focuses: hard technologies, focusing on equipment; moderate, which focuses on knowledge; and light, focusing on relationships.[5] In the Nursing work process, other types of technologies are defined: educational, managerial and care.[6]

Educational technologies aim to facilitate teaching-learning processes; managerial ones aim at the management of care and services; and care, the practice of health care. All come from a technical-scientific knowledge construction resulting from investigations, application of theories, and the professionals' daily experience with users. In general, these technologies enable the diffusion of knowledge and can cause changes, favoring actions that influence the health standard.[6]

Thus, the educational technologies used to mediate the process of health education in the HIV/AIDS context can contribute to broadening access to information regarding the disease, both at diagnosis, access to health services and adherence to treatment, taking into account people's social and family conditions. Educational technologies can thus be an additional device to improve health care, bringing positive perspectives in controlling the virus and its manifestations.[7]

This study was developed from the project entitled: "Health education in times of HIV in the Amazonian context", approved in the CNPq Universal call and held from 2013 to 2016.

In this sense, the objective was to build together with health professionals an educational technology to mediate the process of health education in the HIV/AIDS context.

METHOD

A qualitative approach study was performed, with interface with action research, which is configured as an intervention or resolution of a collective problem in which researchers and participants engage in a cooperative and participatory way to work together with the group, enabling them to explore

their views through reflections.[8] Action research, in its various expressions, broadens the horizons of research, especially in Nursing, to the extent that it guarantees an interface between investigating, acting-implicating and interacting, favoring exchanges, listening, and dialog.[9]

In the case of this study, we decided to perform the technology only with professionals after meeting with the unit's management, who emphasized their interest in empowering the team regarding the production of educational technologies.

The scenario was a reference unit specializing in the care of HIV/AIDS carriers, located in a peripheral neighborhood in Belém-Pará that serves people from all over the state.

All professionals working in the unit were invited to participate. From a total of 15, due to the impossibility of reconciling agendas, the final group had eight professionals from the Nursing, Biomedicine, Social Work, Psychology, and Biochemistry fields.

Data production occurred through development focuses groups. To record the data, a recorder and a field diary were used. The latter allowed recording of the research team's speeches and observations content, involving the description of the environment, the researcher's reflections and perspectives, including his observations, impressions, and findings during this phase of the research.[10]

The focus group starts from group interaction to promote participation, enabling more information and deepening on a given problem. In this research, the name was expanded to development focus group, because, besides the interaction, which was fundamental, there was the participatory process of building the technology according to the information needs for individuals living with HIV, suggested by the participating health professionals.[11]

Four groups were held in the unit's auditorium, lasting approximately two hours each, from October 2015 to April 2016. The dates and times were previously set, according to the professionals' availability. In the days leading up to the meetings, phone contacts were made and messages sent through a mobile phone application to confirm everyone's participation. At the end, we had the next meeting scheduled and a coffee-break offered..

The discussions were guided by a guiding script prepared by the researchers, with questions related to the presentation and content of the technology. The questions were as follows: Do you consider pertinent and/or important to develop an educational technology that helps and contributes to the living good of individuals with HIV/AIDS? In your experience, during consultations, what are the main pieces of doubt and questions they bring? What theme-subjects do you consider important to feature in educational technology in the living good environment of people with HIV/AIDS? For you, what would be the most appropriate educational technology to

contribute and help in the health education process for the living good of these people?

In the first group, the researchers were introduced and an explanation of the research objectives was held, and some types of educational technologies were presented as an example. Subsequently, development activities began with the first question in the script about the importance of a technology to assist in caring for individuals living with HIV/AIDS.

In the second and third, we continued with the reflections that began in the previous group, with questions about the main pieces of doubt and questions from users. Also, it stood out the professionals' experiences in the management of health education processes. Thus, it was possible to discuss the themes and content that they considered relevant to compose the technology.

In the fourth meeting, there was a synthesis of previous discussions, with feedback on the main results found, as well as the decision on the most appropriate format for the technology, intending to contribute to and mediate the health education work process carried out by professionals in the unit.

The corpus of analysis consisted of the recorded and transcribed material, as well as the records in the field diary. This corpus was submitted to thematic content analysis.[12] The following themes emerged from the analysis: the importance of developing an educational technology for the good living of people with HIV/AIDS; main pieces of doubt and questions of people living with HIV/AIDS; the most appropriate technology to contribute to the health education process; participatory development of educational technology, tips for living well.

The study complied with the precepts of Resolution 466/12 of the National Health Council (*Conselho Nacional de Saúde –* CNS) and was approved by the *Universidade Estadual do Pará*'s Research Ethics Committee, Opinion Nº 930,311. The Informed Consent Form was signed by the professionals who were identified by the code (P), followed by the speech order number.

RESULTS

IMPORTANCE OF DRAWING UP EDUCATIONAL TECHNOLOGY FOR THE GOOD LIVING OF INDIVIDUALS WITH HIV/AIDS

There is a set of information that needs to permeate the health education processes because the treatment of the disease itself goes beyond the act of medicating. Such information must be gathered in an educational material both to facilitate the users' understanding and for the work of professionals themselves. In this way, educational technology can mediate the educational process to the extent that it can objectively and directly translate the information considered essential and that users can understand it.

Always in my speech, I put that here in the unit treatment is not just medication […] It is eating, physical activity, emotional activity, condom use […]So, this is it, all this is information that we may be gathering and thus build and create this material here by the unit (P2).

[…] So I understand that educational technology is something shorter and more direct, more basic, in quotes, that gives the user understanding (P4).

The discussions throughout the groups reinforced the need to build material for individuals living with HIV/AIDS and their families that could be used by the entire health team at the time of care when dealing with basic themes for the living well of these people.

Key doubts and questions from individuals living with HIV/AIDS

Based on the pieces of doubt and questions faced by professionals in the appointments, the following themes were considered pertinent to compose educational technology: vulnerability (who gets sick?), Transmission (forms, utensils sharing, affective and/or social relationships, condom use), self-care (hygienic habits, physical activity), control tests such as CD4 and viral load (what are they? What do they serve for? What means? Require previous preparation?), prevention of opportunistic diseases (especially living with pets), food and cultural aspects, such as the routine ingestion of acai berry, a fruit widely consumed in the region, and the medicines' use or the "rheum" of foods.

And how can I transmit it, if I may sleep with my husband, with my son… can I kiss my son? It is this physical contact, the fear of transmission. Not so much to the partner, but your children […] (P1).

It is very important to gradually clarify, slowly the issue of domestic animals, hygienic habits and materials sharing (P4).

Commenting on the conditions that interfere with the self-care of individuals living with HIV/AIDS, the professionals said that these people should not be seen only from the perspective of the disease, but that other dimensions involving the family and their social circles should also be considered.

This guidance for the family is very important, because the patient has this concern, but for whom lives with them the concern is greater […] the greatest fear is

of those who live with. It's important to focus on these people too. We should direct material to them and the relative (P2).

The most appropriate technology to contribute to the health education process

At first, opinions were divided between the elaboration of a folder, poster, guide, serial or booklet. The most important point in this discussion was the possibility of facilitating reading outside the unit. From the discussion, the development of technology in the form of a booklet emerged as appropriate, which can be defined as moderate and light, because it is centered on knowledge and interactions.

I think like this, a poster is a lot of information […] I think it would be a guide, we can't think for us, we have to think for them (P2).

It is important that the material is something that he comes home and read because in the unit there is too much information, at home is quieter (P3).

Participatory development of educational technology "Tips for living well"

The research group drafted the first version of the technology after the first two meetings, considering the answers to the guiding script questions. In the third, this version was presented to the professionals, who when analyzing the content made additions.

I suggest inserting in the technology content that the diagnostic exam is the rapid test or HIV test/serology (P4).

You can also add what is viral load count (P5).

I think I could add in the diet topic the importance of consulting the nutritionist (P2).

How about including regional things, they ask, can I take acai? (P2)

About the graphic presentation, the professionals indicated:

I think the technology has to be something small with a size of 21x15 cm, similar to the one presented at the first reunion (P1, P4 e P6).

[…] *the pages should be white … and the smaller the technology, the better* (P1, P2 e P4).

About the title, the cover and the illustrations, the professionals said:

[…] *I just wanted to suggest not to put on the cover, I don't know if it's possible either, like this HIV/AIDS, because they won't want to take* (P1).

[…] *The title should be "Tips for Living Well"* (P2).

[…] *It would be interesting to put color images in the technology* (P2, P3 e P4).

The suggestion of the title made by P2 was accepted by all. In the final version, the printed brochure-type booklet was called "Tips for Living Well". It was made up of a cover and 10 pages, with a standard formatting size of 25 cm high by 15 cm wide. Each page has up to four illustrations at most, totaling nine illustrations. The summary indicated the 10 topics developed (Table 1).

Table 1 - Summary of the booklet "Tips for Living Well"

Summary
1. Presentation
2. Who can get sick from HIV/AIDS?
3. What is HIV?
4. Where is HIV present?
5. How do you get HIV?
6. How can you not get HIV?
7. What should we know about viral load and CD4 count tests?   • What is the viral load count?   • What are CD4 cells?
8. What are opportunistic diseases?
9. Self-care   • Healthcare measurements concerning personal hygiene   • Healthcare measurements concerning eating hygiene   • Healthcare measurements concerning environmental hygiene
10. Healthy eating   • What does healthy eating mean?   • Important precautions we must take with the foods

DISCUSSION

Regarding the elaboration of educational technology for the HIV/AIDS individuals' good living, the following were highlighted as important: being able to rely on written and routinely available information, providing knowledge and increasing coping skills, aspects considered essential especially for people affected by chronic conditions.[13-15]

Regarding the main pieces of doubt expressed by individuals living with HIV/AIDS, we emphasized that it was considered essential to identify, understand and seek strategies so that the dialogue between professionals and users on the most common questions during care can happen. It was also considered, in the elaboration of the educational material, the living of those to whom it is directed, clarity and the importance of correct information, always based on the intended audience's doubts, which, in the case of this research, resulted from the experiences of professionals who accompany people with HIV/AIDS.[13, 15]

The booklet brings relevant topics and information that enable individuals living with HIV/AIDS to be able to take care of themselves. In the case of the developed technology, we highlight the guidelines on hygiene, care for the environment and healthy eating, as well as essential information on transmission, infection and disease monitoring through specific serological tests, opportunistic diseases, among others.[15]

In self-care, it was considered essential that the individuals seek to identify their needs, reflect on them and build a way to respond to them, with the health professionals' support.[16] Thus, they take the course of themselves, can increase their potential and broaden their perceptions of the offered information.

In the context of life with HIV/AIDS, the quality of life can be guaranteed, as practices that help and enable the person to not only understand but face the disease and possible limitations that may occur as a result of this practice are adopted.[17]

Research shows that the most appropriate technologies to contribute and help in health education processes are those printed with illustrations, simple language avoiding technical terms, and bringing content appropriate to the educational and cultural level of those who will have access to them. This favors the ability, autonomy, and adherence to prevention and treatment conducts.[17,18] The technology chosen by professionals presents itself as a viable alternative to information not only for the person living with the disease but for their family circle, serving as a guide in case of doubt about the most basic questions regarding HIV/AIDS.

The participatory development of educational technology entitled "Tips for Living Well" has made the professionals the technology's authors throughout the process. At each meeting, there was interaction, dialog, involvement, exchange of knowledge and experiences.

The adoption of a participative, communicative and collective approach is recommended in the process of building educational technologies. Interaction and knowledge exchange, considering people's needs and lifestyles, are essential aspects of this process.[19]

Being a collective author, the result of the action research work, means valuing the knowledge and experiences that are intertwined with each participant's life realities,[20] elements that are essential in the search for empowerment.[14] This occurs when

there is an opportunity for the person to gain knowledge of themselves and about their surroundings, and may conduct changes in this environment and their own conduct. It also enables them to define their own problems and needs, understand how they can solve these problems and promote more appropriate actions to foster a healthy and well-being life.[16]

CONCLUSION

The educational technology built with health professionals proved to be of potential use in the reference unit, as the content emerged from the daily practice of the professionals who work there, thus being able to mediate the health education work process.

Although action research has subsidized the development of a technology based on the participation and integration of this unit's health professionals, we understood that this study has as a limitation the small number of participants. Although this amount was sufficient to achieve the proposed objective, it is understood that more professionals would broaden and strengthen the discussion. This was due to the difficulty of participation in the focus groups, because the professionals, although interested and willing to participate, were involved in the work process' intense routine in the unit, making it difficult to reconcile the agenda for the meetings.

We state that the studies must continue in order to validate the developed technology so that it can be recognized for its suitability to the intended audience. The validation will reaffirm the reliability of the technology and facilitate its insertion in the unit to mediate the health education process with individuals living with HIV/AIDS.

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