

ORIGINAL ARTICLES

HEALTH EDUCATION FOR PATIENTS WITH HIV/AIDS: A PROPOSAL FOR INTERDISCIPLINARY INTERVENTION

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ABSTRACT

This is a descriptive study with the aim to develop and implement a proposal for interdisciplinary intervention for health education by means of group activities with people living with the human immunodeficiency virus (HIV) and acquired human immunodeficiency syndrome (AIDS), treated at a health care referral service in Maceió, state of Alagoas, in the Brazilian northeast. The action research was adopted as methodological framework. A total of 84 health education workshops were conducted with 126 people from April 2009 to December 2010, in which the methodology of conversation circles was adopted, and various educational strategies were used, focused on health promotion and quality of life. The topics addressed not only biological aspects, but also emotional issues on the social and affective life of people living with HIV/AIDS. This proposal is a viable strategy and qualifies health care for people living with HIV/AIDS.

Keywords: Health education. HIV Infections. Health promotion.

INTRODUCTION

Since its discovery, approximately 30 years ago, HIV/AIDS has become a global public health problem. Over time, its profile as an acute and terminal disease was modified to a chronic, potentially manageable and treatable condition, a result of scientific advances, especially the use of antiretroviral drugs⁽¹⁾.

Since the epidemic began in 1980 through June 2013, there were 686,478 registered cases of AIDS in Brazil and, out of this total, 88,830 (13.9%) were in the Northeast. In the state of Alagoas, there were 4,843 cases, with an incidence rate of 12.7%. Although national epidemiological data indicate a decrease of approximately 6% in the incidence rate of AIDS cases in the last 10 years in Brazil as a whole, there are significant differences in trends of incidence rates of AIDS in the geographical regions of the country. In the

period between 2003 and 2012, considering all five Brazilian regions, a decrease of 18.6% was observed in the detection rate in the Southeast and 0.3% in the South; however, there was an increase of 92.7% in the North, 62.6% in the Northeast and 6.0% in the Midwest⁽²⁾. These data reinforce the need to integrate all healthcare levels with the structuring of an HIV/AIDS care network with continuous and effective actions in prevention and quality care for people living with HIV/AIDS⁽³⁾ throughout the country, and particularly in regions with higher incidence rates.

Given the chronicity of HIV/AIDS infection, healthcare services and professionals must work in coordination with the objective of providing comprehensive care to individuals living with HIV and their families, as new physical, affective, emotional, social and spiritual demands will arise when living with a chronic, incurable disease, and in

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building affective-sexual, family and social life projects⁽⁴⁾.

From this perspective, investment in comprehensive care and integrated actions is required, challenging multiprofessional teams to build interdisciplinary practice. Nevertheless, some teams of Specialized Care Services (SCS) are struggling to promote comprehensive care and develop interdisciplinary work, contributing to the fragmentation of care in responding to the complexity of AIDS⁽⁵⁾.

The staff working in SCS still suffers strong influence from the biomedical model, which is hegemonic, centered on medical activity and the implementation of procedures, with work processes that are still fragmented and weak in articulations both among the team and with other services and sectors⁽⁵⁾.

In this sense, changes are needed in ways of doing and caring for people living with HIV/AIDS. The implementation of interdisciplinary educational strategies in SCS may be a possibility for changes in the work of health care teams, encouraging an innovative approach through connection between the different protagonists of care, and building a common, articulated care project that values communicative practice⁽⁵⁾.

The educational activities developed by professionals at different levels of health care help individuals expand their understanding of their state of health and the social determinants of living with HIV/AIDS, and encourages a critical position related to the context of their lives and quality of life⁽⁶⁾.

Different strategies can be used in carrying out health education activities, depending on the profile of the population and objectives. Among patients with HIV/AIDS, group activities are a valuable strategy because they encourage the collective experience: the group itself seeks solutions for coping with the disease, greater treatment adherence and improved quality of life⁽⁷⁾.

Considering the importance of educational strategies focused on health promotion and quality of life, the aim of this study was to describe a proposal for a health education intervention through group and interdisciplinary activities with people living with HIV/AIDS treated at a health care referral

center in Maceió, state of Alagoas, in the Brazilian northeast.

METHODOLOGY

This was a descriptive study conducted in several interrelated⁽⁸⁾ stages, using the methodology of action research, in which the process of research and action occur simultaneously⁽⁹⁾. The methodological choice of action research was appropriate since its goal in nursing focuses on care, promoting wellbeing and improving the quality of life of the population⁽⁸⁾.

This proposal was based on the concept that health education is a creative, dialogical process of construction, which requires the recognition of some assumptions for a new practice, namely that health education should encourage the individual to participate in the educational process, and, to this end, should focus on the freedom, autonomy and independence of individuals⁽¹⁰⁾.

This action research study was developed with patients living with HIV/AIDS in an SCS located in a specialized outpatient care center in the central region of the city of Maceió, which develops actions for care, prevention and treatment of people living with HIV/AIDS. It consists of a multidisciplinary team with physician, nurse, psychologist, social worker, pharmacist and dentist. Some of the main activities are: nursing care; counseling and psychological support; care for infectious diseases, gynecology, pediatrics and dentistry; control and distribution of antiretrovirals; pharmaceutical guidelines; monitoring exams; distribution of prevention materials; educational activities for treatment adherence; and prevention and control of STDs and AIDS.

Participants in the intervention included a nursing professor who coordinated the project, 20 undergraduate students in nursing, dentistry and psychology at the Federal University of Alagoas (UFAL), and two nurses and two psychologists from the Brazilian Unified Health System (SUS, as per its acronym in Portuguese). Three other people contributed in the thematic discussions: two professors, including a nurse and a sociologist, and

a member of the community to discuss sexual diversity.

The groups were held twice a week in a private room of the SCS, which protected the confidentiality of information, and promoted a welcoming and comfortable environment for people to express their ideas. Occurring on a monthly basis, the groups were always attended by the students of psychology, nursing and dentistry. On average, there were four students per group, and these prepared a presentation to initiate the activities. One student was chosen as a group moderator, responsible for mediating the discussions together with one professional who was either a nurse or a psychologist from SUS. Throughout the activities, the importance of the multidisciplinary team was shown, because each member contributed with knowledge on their field of expertise, which caused great satisfaction among the participants and students, who accumulated knowledge.

The group members sat in a circle to promote dialogue and exchange of experiences. In each workshop, a pact was made for mutual respect of different opinions, as well as to maintain the confidentiality of the participants.

Before beginning the activities, pedagogical training of students was done through periodic educational workshops: learning spaces with collective and interdisciplinary participation through dialogue, appreciation and construction of new knowledge⁽¹¹⁾. Soon after, the students were divided into task forces aimed at deepening, discussing and addressing various aspects, with focus on health promotion and quality of life.

The action research proposal took place in three different stages.

The first phase was participant observation, which allowed to learn the reality of the study participants and to interact with the context under investigation. A field journal was maintained in January and February 2009. In this phase, the students began to experience the SCS and understand its operation and demand for care, and the reality of people living with HIV/AIDS. The students were also

present in waiting rooms, with the intention of approaching participants and creating a connection with the service, healthcare team and patients living with HIV/AIDS.

In the second stage, discussions were held with the group of patients with HIV/AIDS to present the proposal and discuss the important issues to be addressed, focusing on health and quality of life. From the results of these discussions, the educational activities were started. These results aided initiation of the educational activities; however, new topics could be suggested at the end of each meeting, or the same topic could be repeated with another focus.

In the third stage, weekly meetings were held over 20 months with patients living with HIV/AIDS, which entailed health education activities in which the methodology of conversation circles was used, a method of collective resonance that consists in the creation of spaces for dialogue in which people can express themselves and, above all, listen to others and themselves. This stage aims to stimulate the construction of subjects' personal autonomy through questioning, information exchange and reflection to action⁽¹²⁾. The workshops were quite diverse, depending on the topic being discussed.

Two techniques were used for data collection: participant observation and the field journal, as a tool for recording the data observed.

This project was authorized by the Municipal Health Department and the coordinator of the SCS, and approved by the Research Ethics Committee of the Federal University of Alagoas (protocol 009497/2009-19). All of the participants signed a free and informed consent form.

RESULTS AND DISCUSSION

Through the conversation circles and the themes that emerged from the group, it was concluded that the concept of health and quality of life is very complex, dynamic and involves different factors. The first stage of the study sought to understand the demands and needs of the group, and it was identified that as a chronic condition, managing

HIV/AIDS requires resignification by people living with the disease as well as by healthcare professionals, which would imply changes in care practices currently focused largely on clinical aspects and treatment adherence, to a broader vision of the needs of the population under study. In this stage, a relationship between researcher and study subject was possible.

Moreover, the demands indicated by the group of patients with HIV/AIDS require continuous self-care, learning different clinical aspects as well as changes in attitudes and behaviors that promote coping with the demands arising from the perspective of living with a chronic condition, such as living with the family; life projects (including the decision to have children); fear of getting sick; body changes resulting from lipodystrophy; and fear of revealing the diagnosis and prejudice. These aspects were approached from the topics selected by the group, and presented in Table I.

It is important to emphasize that the topics and discussions were constructed with the group, as the objective was not to transfer information, but to collectively construct knowledge and meaning for the group.

Topics Produced in the Health and Quality of Life Promotion Workshops with Patients Living with HIV/AIDS

A total of 84 workshops were held with the participation of 126 people of both sexes living with HIV/AIDS, who were undergoing clinical care. Participants could attend more than one meeting/workshop.

From these meetings, 10 themes were defined in the educational workshops, all of which focused on health and quality of life of people living with HIV/AIDS. These were: quality of life; eating habits; physical activity; adherence to treatment; love and sex life (preventive behavior); leisure; social life; and family planning (Table 1). Different strategies were used in the workshops, and at the end of each one, the topic of the next meeting was discussed and defined with the group.

It is important to emphasize that from one central topic in a conversation circle, other issues arose and were concurrently discussed, providing the experience of the deconstruction

process and search for learning, enabling a new way of thinking and acting in the daily lives of the participants, providing the creation of spaces for discussions essential to overcoming fears and taboos, and breaking prejudiced and discriminatory attitudes, all of which are very important to addressing issues related to HIV/AIDS.

These results indicate that the methodology used was appropriate because it allowed interaction and dialogue between formal and informal knowledge, leading to reflections and changes in health care practices, with a proposal to build collective knowledge.

Different educational strategies (with an emphasis on active methods) were used when treating different topics. In addition to motivating the group, the strategies encouraged receptiveness, providing discussion and reflection of the participants. Guidelines prescribed as “ready fixes” and outside the context of the reality of the participants were avoided because they are ineffective and do not result in health education⁽¹⁰⁾. Moreover, aspects were approached based on a broad concept of health, and prescriptive, individualized and coercive actions were discarded and replaced with an approach of helping the group to think, rather than dictating what to think⁽¹³⁾.

This space for dialogue allowed the creation of connections and listening suited to the needs of individuals living with HIV/AIDS. Group activities promote the encounter between people who share common situations in everyday life, providing them with access to information and the exchange of experiences, contributing to the prevention of morbidities and health promotion. Group activities stimulate spaces of humanization, social inclusion and citizen participation to better cope with the disease, greater treatment adherence and better quality of life⁽¹⁴⁾.

Group work fosters and promotes identification with other people living with HIV/AIDS through the exchange of experiences, helping to build a sense of identity, which functions as a continent of anxieties, developing bonds and socialization, stimulating self-knowledge, and helping these people to deal with their emotions and

limitations, and recognize their value⁽¹³⁾.

The topics addressed in the group sought to contribute to individual and collective awareness of people about their health and quality of life, and provide a discussion on their rights to health care and empowerment of the study population as citizens and SUS users.

Since the discovery of HIV, the technical

and scientific developments - especially after the advent of antiretroviral therapy - gave people living with the virus the opportunity to reconsider their life projects and reframe their lives, enabling, among other aspects, the transformation from the idea of certain death to a chronic condition, modifying values, beliefs, habits and individual and collective knowledge⁽¹⁵⁾.

Table 1 - Issues discussed in educational workshops with people living with HIV/AIDS - Maceió, 2009-2010.

Workshop/ Theme	Development Proposal	Strategies/Facilitating techniques
Quality of life	Discuss aspects of the everyday that promote quality of life; Discuss aspects that encourage quality of life (Family relationships, work, friends, leisure); Identify the difficulties faced through the statements and group discussion.	Warm-up: participant introduction and welcome. Discussion on expectations of the group. Theme development: What does quality of life mean to you? Group discussion on ways of seeing life and quality of life. Group reflection.
Eating habits	Through an activity with a menu, identify what people are eating; Discussion about the advantages of a healthy diet; Develop a poster with meal plans.	Warm-up: introduction of participants and warm-up. Discussion on eating habits. Topic development: what does a healthy diet mean to you? Group discussion on ways of eating and how this affects everyday life. Group reflection.
Physical activity	Address and encourage the importance of regular physical exercise; Identify whether anyone in the group practices physical exercise; Question what are the benefits of physical exercise; Encourage walking, swimming and other activities.	Warm-up: introduction of participants and welcome. Conduct stretching technique. Topic development: why is physical activity important? Group discussion about types of exercise and how they affect quality of life. Group reflection.
Treatment adherence	Question what difficulties are encountered in treatment adherence; Reflect on treatment adherence; Advise on methods to facilitate taking drugs; Develop strategies with users to facilitate the day-to-day.	Warm-up: Introduction of participants and welcome. Video presentation on the interaction of HIV in the body. Topic development: what does it mean to adhere to treatment? Group discussion on the importance of adherence to treatment and how it can improve quality of life. Group reflection.
Preventive Behavior	Question participants about the risk of reinfection; Advise them on why condoms should be used; Group activity putting condoms on prosthetics.	Warm-up: introduction of participants and welcome. Video presentation about relationships and safe sex; Topic development: what is the importance of prevention? Group discussion on the risk of re-infection and its consequences.
Leisure	Identify in statements which leisure activities promote pleasure; Advise participants about the importance of leisure for treatment; Encourage group leisure activities.	Warm-up: introduction of participants and welcome. Use of music for relaxation. Topic development: what is leisure? Group discussion on how leisure affects quality of life. Group reflection.
	Discussion on isolation and prejudice; Reflect on the importance of social,	Warm-up: introduction of participants and welcome. Video presentation on social groups.

Social Life	family and emotional interaction; Discussion on the main difficulties encountered in everyday life, and the search for solutions; Explain the free psychological assistance offered by the SCS unit.	Topic development: why live in a community? Group discussion: isolation and prejudice/connections/appreciation. Group reflection.
Family Planning	Discussion on the desire to have children, seeking to identify the this desire in statements; Reflection on possibilities and difficulties of being a mother/father; Advise them on the use of contraception; Advise them on the importance of prenatal care.	Warm-up: introduction of participants and welcome. Video presentation: dream of being a mother. Topic development: can I have children? Group discussion about the desire of maternity and paternity. Group reflection.
Self-Esteem	Reflection on self-esteem; Discussion on the importance of self-esteem; Advise on free psychological assistance in the SCS unit.	Warm-up: introduction of participants and welcome. Realization of mirror activity. Group reflection on limitations and qualities as a person: do I value myself? Group discussion: valuing individual qualities and capabilities.
Living with HIV/AIDS	Reflection about living with HIV/AIDS as a chronic condition. Facing prejudice.	Warm-up: introduction of participants and welcome. Video presentation on people living with HIV/AIDS. Group discussion about what has changed in daily life since diagnosis. Group reflection: am I happy?

This change should also occur in the practice of healthcare professionals, so that the actions of health education enable the recreation of participatory, interactive, cooperative and inclusive moments, bringing together and humanizing interpersonal relationships, ensuring access to prevention measures, as well as ensuring the production of comprehensive care, capable of promoting health⁽¹⁴⁾ and performing interdisciplinary practice.

In this sense, the conversation circles addressed issues that contributed to health care and quality of life, and valued - beyond the biological aspects - the emotional, social and emotional aspects of living with HIV/AIDS.

Through the bond established with the users, the importance was shown of a comprehensive, cohesive approach to the care of these patients, since despite the SCS having a multidisciplinary team, its work is not yet interdisciplinary. Greater attention should be given to health education and group activities for this population. Group health education can be an important strategy for mutual growth that promotes reflection and participation, and helps to minimize suffering, deal with

expectations and emotions, and promote citizenship and quality of life⁽¹⁴⁾.

Educational activity is complex and requires theoretical and practical tools so that it can occur and achieve the goals proposed. This points to the need for pedagogical training among nursing students⁽¹⁶⁾ and other students in the area of health. Furthermore, it is essential to change current health care practice, which is focused on the biological model. Hence, it is necessary to sensitize and train healthcare professionals working in clinical practice. The needs of people living with HIV/AIDS should be recognized in a comprehensive and humanized approach, and include partners and family in care and routine health services⁽¹⁷⁾.

As a member of the healthcare team, the nurse has a fundamental role in caring for people living with HIV/AIDS, and plays an important role in the development of actions for health education in different care settings, contributing to a biomedical paradigm shift for a broader concept of promoting human health, as important changes have occurred in nursing, supplanting the traditional mode of education and enabling the realization of effective action

for health promotion and health in different care settings, with diverse populations in all stages of life, living with chronic diseases or not⁽¹⁸⁻¹⁹⁾.

On the issue of change, the training of nurses is still focused on the biomedical model. Yet the use of group activities can be a valuable space for the implementation of the biopsychosocial model, ensuring more humanized and contextualized quality care⁽¹³⁾. This strategy has been considered effective to socialize and disseminate knowledge and encourage the teaching-learning process, making the dynamic more enjoyable and interesting for the qualification of nurses⁽²⁰⁾. Furthermore, these activities can involve the healthcare team, seeking an interdisciplinary, dialogical and participatory practice based on mutual respect.

FINAL CONSIDERATIONS

This project constitutes an innovative intervention in the service studied, as it drafted and developed health education activities in a dialogic, emancipatory and ethical perspective, qualifying health care together with patients living with HIV/AIDS.

This proposal is a successful experience, with the possibility of being implemented in healthcare services at a low cost, and with great potential to impact the construction of bonds between the healthcare team and its users, and encouraging the construction of interdisciplinary practice. In this sense, group practices should be encouraged, implemented and accredited as a first step towards changing the current prevailing model.

Educational activities focused on health promotion and quality of life constitute a space for promoting mutual learning that is

collectively constructed, interdisciplinary and dialogical, contributing to the construction of new knowledge by the participants, and the ability to work in a group: learning how to listen, be sensitive to the problems of individuals and, above all, be able to maintain an open dialogue and respect the autonomy of patients.

The action research allowed for a very close interaction between researcher and study subject, which is a challenge for the researcher, but also in rich learning opportunities for both. The appreciation of health education for people living with HIV/AIDS and their families is essential. The challenges of the demands stemming from chronicity of HIV infection are permanent and include the (re)construction of life and professional projects and the need to maintain treatment adherence, imposed by the need to improve the quality of life of these individuals.

Such actions are expected to be incorporated by the SCS with the interdisciplinary participation of SUS professionals, and this integration of teaching/service must be increasingly close, since they are live spaces for learning. Such integration may be capable of causing changes in current healthcare practices and also modifying healthcare training.

This proposal brought many positive impacts to the population served by encouraging the empowerment of individuals with regard to their rights as citizens and SUS users, and the opportunity to provide comprehensive care, namely the human being as a biopsychosocial subject. Also noteworthy is the contribution to better integration of teaching and service, building a closer relationship between reality, social needs and healthcare interventions.

EDUCAÇÃO EM SAÚDE JUNTO ÀS PESSOAS COM HIV/AIDS: PROPOSTA DE INTERVENÇÃO INTERDISCIPLINAR

RESUMO

Trata-se de um estudo descritivo que teve como objetivo elaborar e implementar uma proposta de intervenção para educação em saúde, de maneira interdisciplinar, por meio de atividades de grupo junto às pessoas vivendo com o vírus da imunodeficiência humana (HIV)/aids atendidas no serviço de referência, na cidade de Maceió-AL. Adotou-se como referencial metodológico a pesquisa-ação. Foram realizadas 84 oficinas de educação em saúde com 126 pessoas no período de abril de 2009 a dezembro de 2010 durante as quais foi adotada a metodologia de rodas de conversa, e diversas estratégias educativas com o enfoque na promoção da saúde e qualidade de vida. Os temas abordados valorizaram, além dos aspectos biológicos, as questões emocionais da vida social e

afetiva das pessoas com a infecção pelo HIV/aids. Tal proposta é uma estratégia viável e qualifica o cuidado em saúde junto às pessoas que vivem com o HIV/aids.

Palavras-chave: Educação em saúde. Infecções por HIV. Promoção da saúde.

EDUCACIÓN PARA LA SALUD A PERSONAS CON VIH / SIDA: PROPUESTA DE INTERVENCIÓN INTERDISCIPLINAR

RESUMEN

Se trata de un estudio descriptivo que tuvo como objetivo desarrollar e implementar una propuesta de intervención para la educación sanitaria de manera interdisciplinaria, a través de actividades de grupo con personas que viven con el virus del la inmunodeficiencia humana (VIH)/ síndrome de inmunodeficiencia humana adquirida (SIDA) atendidos en servicios de referencia en Maceió-AL. Fue adoptado como un método de investigación-acción. 84 talleres se llevaron a cabo la educación sanitaria a 126 personas entre abril de 2009 diciembre de 2010 en las que se adoptó la metodología de los círculos de conversación utilizando diversas estrategias educativas con un enfoque de promoción de la salud y calidad de vida, cuyos temas valorada dirigida, más allá de los problemas emocionales, biológicos, la vida social y afectiva y que viven con VIH / SIDA. Esta propuesta es una estrategia viable y cumple los requisitos de salud para las personas que viven con el VIH / SIDA.

Palabras clave: Educación para la salud. Infecciones por VIH. Promoción de la Salud.

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