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Life experiences of HIV/AIDS carriers in terms of the perspectives of the promotion of health

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ABSTRACT

Aim: The objective was to learn about the experiences of HIV/AIDS carriers attending a self-help group founded as part of the Health Promotion program. **Method:** This is a descriptive study of a retrospective character, using qualitative analysis. Data was collected from the records of a self-help group involving HIV-infected patients in an outpatient clinic specializing in infectious diseases in Fortaleza, Brazil, between February and October 2010, and analyzed. **Result:** The results were categorized into: (1) Knowledge: when there is the incorporation of new concepts of fact or phenomenon; (2) Motivation: when it is linked to personal attributes that modify the desire of the subjects; (3) Adherence: when it involves a collaborative process where involves the subjects' participation in their treatment decisions and (4) Behavior Change: when it is associated with a positive or negative conditions in their lives. **Conclusion:** The educational actions developed in the group activities had great importance in the teaching and learning processes for the creation and transformation of the subjects involved.

Keywords: Acquired Immunodeficiency Syndrome; Health Promotion; Health Education; Group Processes.

INTRODUCTION

There are many changes in the mortality and morbidity profile related to the Acquired Immunodeficiency Syndrome (AIDS) and the Human Immunodeficiency Virus (HIV) due to the advances and availability of treatment such as antiretroviral (ARV) drugs, and the attention offered to patients. Nowadays, people diagnosed as being HIV seropositive have shown an increased survival rate⁽¹⁾.

However, in the therapeutic proceedings it is necessary to ensure the efficacy of the actions to promote health that strengthen the changes in lifestyle of HIV carriers or of those in treatment. It is still the case that for HIV carriers, a positive diagnose is a shock which generates traumas of a physical, emotional and social nature⁽²⁾.

AIDS can be characterized today as a chronic disease which requires that the health professional should promote opportunities for those who live with this illness to help them face their health problems which are related to other aspects of their quality of life, from their personalities to the social and family context in which they live⁽²⁾.

HIV carriers have to deal with many situations that affect their lifestyle and, by extension, the way they come to deal with their illness. Learning more and sharing the experiences of the pathology, the HIV carriers acquire the means to perform autonomous actions for their own benefit and that will allow a better quality of life.

Group experiences constitute strategies by which the participants can share knowledge, experiences, expectations and feelings that can help to lead to changes in behavior with regard to health. The development of such experiences can result from the creation of a therapeutic group and an educative group.

The therapeutic group is characterized by the emphasis of the processes of self-help as a method to promote personal growth, development and the improvement of the inter-relationship of the supportive networks, using an experimental process. Using this process, the participants develop and improve feelings of trust, building ties of sympathy and empathy with the other members of the group, aiming to know themselves better and the others in a complete sense, generating social improvement and mutual help⁽³⁾.

In educational terms, the actions done aim to modify the habits and behavior of the participants through the problematization and reflection of the health problems that affect the people in the group. This aids the socialization, reciprocity and trust among them and the health professionals, and, in a wider sense, promotes health⁽⁴⁾.

The interface between the experiences of group members is based on the objective of proportionate activities aiming to change the behavior of the individuals, focusing in their lifestyles, placing them in the center of their families and the cultural environment of the community to which they belong.

Both are based on an understanding that health is a product of many factors which are related to the quality of life, including an adequate standard of nutrition, housing and sanitation, good working conditions, opportunities for education throughout life, social support for the families and individuals, a responsible lifestyle, and an adequate spectrum of health care⁽⁵⁾.

Other favored aspects of these experiences are empowering and autonomy strategies, which are tools of very great importance to the promotion of health. These not only motivate the individual to legitimate and make possible the expression of marginalized groups, but also promote the destruction of barriers that are the source of limitations with regard to the enjoyment of a healthy life. As a consequence, it is important that nurses offer professional intervention to provide grounds for this construction, and also offer knowledge for the acquisition of new behavior⁽⁶⁾.

It is in this context that the HIV carrier is placed, facing re-adaptation to a lifestyle that demands a complex process of healthcare. The patient's learning is inherent to the process, and it is necessary that the individual acquires the possibility of choice within the his or her context of health/illness^(3,7).

Thus, this study presents reports of the group experiences of patients diagnosed as being HIV seropositive, among whom we call attention to those who have an educational focus. Education in health believes that the changes in behavior happen when the participants start to adopt a critical view which is based on reality, with permanent exchanges of

information related to the construction of conduct, aimed at the adoption of healthy habits to achieve a better quality of life⁽⁷⁾.

To conclude, this study of patients diagnosed as HIV carriers who are participants in a self-help group, has the objective of identifying the therapeutic processes that empower education in health in a hospital environment, with a focus on self-healthcare.

METHOD

This is a documental and descriptive retrospective research, using qualitative analysis. This approach permits us to express the sense of the phenomena in a social world, situated between data and theory⁽⁸⁾.

The documentary study uses strict data sources (documents) whether written or not, in the form of primary sources. This information can be generated at the moment of the event or phenomenon, or later⁽⁸⁾.

The data used in this research originated in the forms filled in by the facilitators after group activities on the part of HIV carriers were carried out, during the period February to October 2010, in the specialized clinic for infectious diseases of the College Hospital Walter Cantídio (HUWC, in Portuguese), of the Ceara Federal University, in the city of Fortaleza, Brazil. The self-help group started in 2006 and constituted one of the activities developed by the project "Study Group of HIV/AIDS and Associated Diseases Nucleus" (NEAIDS, in Portuguese), that aimed to promote education in health on the part of the infected, and prevention of other aggravated situations. It also constituted a place to guide health professionals, leading to the production of knowledge.

The self-help group was open access; it was held on a weekly basis in an appropriate environment, with an average duration of one hour. The invitation to participate in the group was extended to all patients. Anyone who wished to participate, after confirming their presence by making a clinical appointment, would voluntarily turn up at the location. A nursing team mediated the group. The nurse was the mediator of the topics discussed by the group, and an academician in Nursing used to take notes on the

conversation that took place. For the note taking, the researchers used a proforma developed for this study, which included the following questions: gender, age, comments and testimonies of the participants, and the topics debated during the group discussion. The comments and testimonies, and the themes discussed, were collected in 33 group meetings, at which 53 patients were present. In each session, between two and six patients participated in the group.

The testimonies and comments of each participant were treated individually; the group reports were reviewed, then read and re-read to guarantee the veracity of the information.

To analyze the content developed in the group meetings, the technique of content analysis was used. This deals with written text manuals or, in other words, with the linguistic materiality through the empiric conditions of the text, in an attempt to understand the thinking of the subjects through the content expressed in the text. This was done through a transparent conception of language and by establishing categories for its interpretation⁽⁹⁾. This analytical technique is composed of three major steps: 1) pre-analysis: the organization phase, during which many proceedings were carried out, such as floating reading, hypothesis and objectives identification; 2) the exploration of the material, in which the data is coded from the units of registry (minutes, papers, reports, etc.); and 3) the treatment of the results and the interpretation, through categorization. This consists of classifying the elements according to similarities or differentiation, with a subsequent regrouping based on common characteristics. Therefore, the following categories were created: Acquaintance, Motivation, Adhesion, and Change of Behavior.

It is important to mention that this study was approved by the Committee of Ethics in Research of the Ceará Federal University, under protocol number #249/09, under the norms established by the Brazilian National Health Counsel, that regulated the research into human beings by the Resolution #196, of October 10th 1996⁽¹⁰⁾. To preserve the identity of the participants, letters were selected randomly to identify them.

RESULTS

The identification of the therapeutic processes developed in the group sessions was divided into categories that may or may not be associated with the objective of facilitating the understanding of strategies of education in health developed by the self-help group as a service of specialized assistance.

Acquaintance

We understand that to know something is to say that we incorporate a new or original concept about a certain fact of phenomenon. Knowledge does not start from a position of emptiness, but from experiences accumulated throughout life, as a result of the interpersonal relationships and the reading of many books and articles by the researchers⁽⁶⁾.

The supply of information and/or the evaluation of the lived experiences are not a learning guarantee for the individual⁽⁶⁾, as the information provided during the group sessions must be tested by developed an experienced understanding. In the case of positive seropositive patients, fear and the non-acceptance of the positive diagnosis were observed. However, with the acknowledgement of the illness, individuals confirmed an improvement in their daily routines.

I am accepting my problem, and I have to continue... Now I know how to take care of myself... Au

I've found that was HIV positive during pregnancy. But my son is healthy and my husband is HIV negative, and now I know how to live with serodiscordance and I try to have healthy habits... Ao

It's been hard, but I have tried to be informed about the topic so I can relax more. It helped me a lot. Cl

A way of acquiring information by the subjects happens through the information provided by the elements of mass media that, if well used, can generate understanding among the population about the health issue that exist.

I follow the news and the discoveries about our struggle against STDs and AIDS... Ds

I inform myself using the Internet. My doubts in the beginning were very simple. Rn

These quotations demonstrate the interest of the individuals to learn more about the disease, which they recognize they don't have enough of. They are motivated to search for this information about the illness as a way to perceive the disparity between the actual state of health and their expected state, always looking for ways of encouraging healthier behavior.

Knowledge can generate reflection and spur action towards the development of improvements in the quality of life of these patients.

Motivation

This is a word that comes from the Latin *movere*, which means, "to start a movement". It has also been defined as a psychological force that "moves" a person to perform some kind of action. At the same time, it can be described as the will on the part of the apprentice to get involved in learning, which readiness can then be understood as evidence of motivation⁽¹¹⁾.

This speech highlighted the willingness to live and an eagerness to postpone death:

We all can die. I just don't want to die now. Jc

Related to the environmental influences, it was observed that the environment can create, promote or reduce the state of receptivity to learning. A pleasant environment, which is comfortable and adapted to the needs of the patients can change the state of readiness to learn⁽¹¹⁾. The environment of the public system of health, or in the case of this study, the self-help group, influences the relationship of the client with their state of

health, and affects that person's willingness to participate in behavioral actions that promote health, as observed in the following comments:

I like this group a lot. It is helping me to treat my depression and I have even made some friends. Ar

The group is really good and I am sorry for those who do not participate. Cr

Under this scenario, it could be seen that the motivation of the users in was in terms of their participation in the group, and how they evaluated the way it had helped them to confront the challenges of their illness.

Ultimately, there are networks that aid the development of learning, that are represented by dear friends and family members, by the community and by the professional-patient interaction.

I am not afraid to complain. my life is good. I'm happy and I love my family, because they support me. Is

I live very well and my kids support me in everything I do. Nd

In this study, only the relatives were mentioned within the social network, motivating these individuals to deal with the sickness from a happy perspective. On the other hand, friends were mentioned as a symbol of abandonment:

Before the diagnosis, I had a vast number of friends. Now they are all gone. Je

In the relationship between professionals & patients, the individuals not did not declare the belief that the health professional was the sole promoter of change and of educational activities, nor as the holder of certain knowledge which would place them outside the group.

Adhesion

Adhesion is a collaborative process that helps the acceptance and integration of a certain therapeutic regime in the daily lives of people in treatment, supposing that they have participated in the treatment decisions themselves⁽¹⁾. Thus, the search for the proper use of ARV drugs is the main focus so that people who are HIV carriers can enjoy the benefits of a systematic use of the treatment provided.

In this process, the following comments were noted:

I have taken my medication since 2004, the year of my positive diagnosis, and I never let myself stop taking them. Sm

I take the drugs correctly, one in the morning and the other at night. Md

To consider that the ARV drugs are being used correctly and incorporated into the daily routine of the seropositive patients, it is necessary to motivate them to adhere to the treatment, as the therapeutic regimes are complex. Among the difficulties, there are a large number of drugs and it is necessary to store these drugs at a low temperature. In addition, size of the medication makes it difficult to swallow. In addition, there is a conflict generated by the daily schedule of doses in the lives of the patients.

Within this context, people have the right to make their own decisions regarding the plan of action for their health developed by the professional that aids them. This systematic and decisive attitude was represented in the comments that follow:

I am very rigorous with my drug schedule. Pd

I take my medication regularly and if I just miss a drug if it's over. Yet this is not likely to happen. Nd

In the case of the use of antiretroviral medication, there are many factors that influence the non-adhesion, a term that describes the resistance of the client to accept the therapeutic regime prescribed for the specified treatment⁽¹¹⁾. Among them, there are the collateral effects produced by taking the medication, as mentioned in the following comments:

In the beginning of taking the medication I had a lot of headaches, I lost weight and I had a constant fever. Pd

I started medication 30 years ago, and initially I felt dizziness and discomfort, but now I am adapting to the medication. Rr

I had many reactions to the cocktail of drugs. Ar

Complete and full adhesion is a non-reachable proposal, as in some situations such non-adhesion is the decision of the individual, and works as a defense mechanism with regard to a the stressful situation. Then, the client can leave the routine of treatment to maintain or increase the learning situation, which can always be considered beneficial for the patient⁽¹¹⁾.

In this sense, the success of this educational program resulted not only in a satisfactory degree of adhesion to, and an acceptance of, the proposed treatment, but it also motivated patients to accept a regime which promoted their health.

Now, after coming to the group, I take my medications as if it was water. Nd

Changes in Behavior

The changes in behavior demonstrated that the maintenance or otherwise of these changes can be associated with the positive or negative consequences for the lives of the people concerned. In this sense, the changes in the routine or lifestyle due to a positive diagnosis of AIDS, will require, from the patient, the adoption of new behavior patterns and the abandonment of others, in order to maintain their quality of life⁽¹²⁾.

As such, it is necessary to adopt a healthier lifestyle, adequate and natural, aiming to isolate the illness⁽⁶⁾.

Such changes of habit were observed in the following comments:

Since the diagnosis, I've stopped drinking. Ed

I used to drink a lot, but now, after I found out, I don't drink anymore. Cr

I've stopped drinking and I'm much better with my wife... I'm fine, thank God.
Es

Besides ceasing the drinking of alcohol, comments verified a preoccupation with diet and physical activity:

I have a good diet and whenever I can, I jog. Is

I have a balanced diet and this helps me a lot. Rc.

Another aspect related to health that deserves to be mentioned is the use of contraceptives, as noted by only three members:

I have healthy habits and now I wear condoms every time. Ao

I have been worried about my life regarding my diet, drinking and the use of condoms, and I've been gaining weight, too. Ma

I never liked to eat, but I wear condoms every time I have sex. Gd

This leads to the reflection about the importance of the use of educational steps to motivate the adoption the use of contraceptives, as it is one of the topics highlighted in all contacts with the health professionals, constituting the main tool in the fight against the sexual transmission of AIDS. It is professed that all carriers, either the serodiscordants or the seroconcordants, must use contraceptives, since the lack of their use with a seropositive partner makes it difficult to control the viral load and facilitates the risk of an ARV resistant virus¹. It is interesting to observe that the fact that one recognizes oneself as an HIV carrier does not imply the abandonment of the use of contraceptives, even with a non-carrier partner or of unknown serology⁽¹³⁾.

DISCUSSION

The health education uses the theoretical references that transpose the deterministic notion of instituted knowledge and the practice of health⁶. These known references are

the ones that guide the development of the discussion of the results. When we evaluated the categories of education in the area of health, we observed the importance of life histories, the acquired beliefs and the developed social values, and also the importance of the subjectivity of each subject that is part of this accumulation of experiences that constitutes knowledge⁽⁶⁾. Educational intervention in health must resort to these pre-established areas of knowledge on the part of individuals, looking to adopt new behaviors through a set of collective strategies, aiming to find the individual autonomy that allows them to achieve their empowerment.

Motivation is the result of intrinsic and extrinsic factors which can help or block the motivation to learn. These factors can be classified as these main categories, but which are not mutually exclusive: personal attributes, environmental influences and developing social networks⁽¹¹⁾.

Adhesion to drug therapy is extremely important for the success of the treatment of patients, especially when there is the use of ARV, as it aims to reduce the morbimortality and improves the quality of life of people by acting on the viral replication, which slows or avoids the onset of immunodeficiency. The treatment progressively reduces the viral charge, and the maintenance and/or restoration of the functioning of the immunologic system⁽¹⁾.

It was observed that the development of the group activity among the clients who were HIV carriers promoted the exchange of individual experiences that represented a powerful educational environment, where the solutions to the problems were exchanged among the members of the group that, helped by the mediator, will generate adhesion to the necessary drug and behavior therapies.

The positive changes done to the participants of the group probably were not a result of the healthcare given, but also due to their presence in the group, which gave them an opportunity to be heard. Then, at the same time they could contribute to others with their own personal experiences. The end result was that they can be supported to understand their illness better, developing feelings such as comprehension, which helps them to develop a group of attitudes that promote growth, or therapeutic, referring to

themselves. Thus, the change in behavior was evidenced as something important to the improvement in the quality of life of the patients.

CONCLUSION

In this study, it was observed that the use of a self-help group strategy benefitted the health education of HIV carriers and, consequently, assisted the improvement in their quality of life, as it was seen that the sharing of experiences lived by the members of the group expanded each patient's self-awareness and created important tools to promote health.

The educative actions developed in the group sessions have a great part to play in the process of teaching and learning as a means of creating and transforming the subjects inserted into this context. As such, the spontaneous participation, autonomy and valuing of the individual knowledge of the participants is essential.

The health education developed in the group sessions was aimed to motivate subjects to adhere to the therapies offered, and to change their behavior, as well as to affirm the information shared as a means of promoting emancipative and libertarian actions to achieve self-care. Therefore, it can be affirmed that these objectives were achieved, as in the discourses of the subjects it was demonstrated that the categories of health education identified, allowed changes in practice and reframed their decision-making.

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