ABSTRACT

Objetivos: reportando los efectos psicosociales evidenciados en pacientes con el síndrome de inmunodeficiencia adquirida (AIDS) y proporcionando acciones de enfermería que permitan minimizar estas necesidades psicosociales evidenciadas. Método: estudio descriptivo, del tipo relato de experiencia, envolviendo a seis pacientes con diagnóstico de AIDS, desarrollado en el Servicio de Infectología de un Hospital Escolar, durante el periodo de noviembre de 2013 a febrero de 2014. La recolección de datos se realizó mediante técnicas de observación asistemática, comunicación verbal e no verbal establecidas en el momento de la prestación de cuidados de enfermería durante el estadio curricular obligatorio en Infectología. Resultados: los principales efectos evidenciados fueron: la negación de la enfermedad, las dificultades financieras, las alteraciones emocionales, las repercusiones familiares y el estigma social. Conclusión: una atención integral y holística a los pacientes con AIDS es primordial y la enfermera debe estar preparada para proporcionar las acciones de enfermería que permiten minimizar las necesidades psicosociales evidenciadas.

RESUMO

Objetivos: relatar as repercussões psicossociais evidenciadas em pacientes com o síndrome da imunodeficiência adquirida (sida) e apresentar ações de enfermagem que possibilitem minimizar as necessidades psicossociais evidenciadas. Método: estudo descritivo, do tipo relato de experiência, envolvendo seis pacientes com diagnóstico de AIDS, desenvolvido no setor de infectologia de um hospital escolar, no período de novembro de 2013 a fevereiro de 2014. A coleta de dados foi realizada mediante as técnicas de observação asistemática, comunicações verbal e não verbal estabelecidas no momento da prestação de cuidados de enfermagem durante estágio curricular obrigatório em infectologia. Resultados: os principais efeitos são os evidenciados foram: a negação da doença, as dificuldades financeiras, as alterações emocionais, as repercussões familiares e o estigma social. Conclusão: a atenção integral e holística aos pacientes com AIDS é primordial e o enfermeiro deve estar preparado para prestação de cuidados que potencializem o enfrentamento dos problemas de ordem psicossocial. Descritores: Síndrome de Imunodeficiência Adquirida; Cuidados de Enfermagem; Apoio Social.
INTRODUCTION

The acquired immunodeficiency syndrome (AIDS) is an infectious disease caused by the human immunodeficiency virus (HIV), the main route of infection is sexual.\(^1\) HIV infection and the development of AIDS, dating from the 80's, more notably in 1981 in the United States of America (USA) and 1982 in Brazil, being initially associated to the practice of homosexual sex, illicit drug users and sex workers.\(^2\)

This context of emergence of the syndrome, permeated by a symbolism of practices and young people behaviors, the disease has enriched the moral and social values, reflected even today. Although it has occurred dynamically, epidemiological and social changes those confer distinct characteristics of those that marked its emergence. The disease spread to other social classes and population groups such as heterosexual, monogamous women, the elderly and even children.\(^2\)

The AIDS diagnosis carries significant consequences, not only regarding physical health, but also emotional, social, psychological and ethnic linked since the beginning of the disease. When faced with the seropositivity of the HIV virus, or being manifesting the disease, the individual may experience many stressful situations those often exceed their resilience. Regarding love and gregarious needs, these individuals can envision situations of losses, similarities and differences of loved ones, due to issues such as stigma, mental and physical changes resulting from the disease and the impact that the diagnosis triggers in the psychosocial life of that individual.\(^1\)

Considering the various psychosocial effects that these individuals can experience, the actions and nursing care become of paramount importance to increase the potential of coping by these individuals. The nurse, when caring for people diagnosed with AIDS, should use actions those address the coping strategies in an individualized and holistic way, encompassing physical and mental health and social and cultural conditions embedded in the health-disease process.

It is known the nurse's role as an active agent in this process and knowing their relevance in the care of the individual as an integral being, then emerged the need to report this experience that occurred during the care of individuals diagnosed with AIDS. Associated with this, in this experiment, it was observed that most of them, externalized various psychosocial demands, which justify and make this study relevant, because it demonstrates the need to carry out the provision of nursing care that meets their psychosocial needs. It also emphasizes the importance of providing a humanized care, assistance to overcome the technicalities and often biased to patients with AIDS; the nurse should recognize that this is a paradigmatic disease and of multifaceted repercussions.

Facing this scenario, it reinforces the need to meet the psychosocial aspects those permeate the everyday life of AIDS patients. From there, it can meet nursing actions those can help these individuals overcoming adversity to the disease and its psychosocial burden. Based on the foregoing, the objectives of this study are:

- Reporting the psychosocial effects evidenced in patients with acquired immunodeficiency syndrome (AIDS)
- Presenting nursing actions those allow minimizing evidenced psychosocial needs.

METHOD

This is a descriptive study with an experience report, which was conducted from November 2013 to February 2014 from the experiences of students of the nursing graduate course of the Federal University of Campina Grande, in the discipline Supervised Internship II. The study setting was a university hospital in the city of Campina Grande-Paraiba, and the location was the sector of Infectious Diseases, which is a benchmark in the treatment of AIDS patients and HIV-infected.

The study site comprises six wards with two beds and two isolates, and provides services to various infectious diseases. The nursing team consists of 11 practical nurses, one nurse and six nurses, being everyone on duty.

The study included six patients diagnosed with AIDS. Data collection occurred during nursing care, where students were able to identifying by means of the techniques of therapeutic communication, verbal and nonverbal communication, in addition to systematic observation, psychosocial needs faced by these individuals. It was used a diary where was held the major notes those focused on the situations reported to psychosocial problems.

The results were categorized into psychological repercussions of order of psychological-acceptance of the disease and resilience versus denial of the diagnosis; emotional changes resulting from disease
diagnosis and impact of social order - ignorance about the disease; financial difficulties; family problems and social stigma. Thus, the data obtained are discussed obeying triangulation: psychosocial consequences highlighted in the subjects of the literature and the authors’ view.4

Noting that this study followed the ethical principles, respecting the privacy and direct patients, because it is an experience report constructed from a look of psychosocial needs those affected these subjects during the provision of nursing care, not thus violating the ethical principles.

RESULTS AND DISCUSSION

• Impact of psychological order
• Acceptance of illness and capacity of resilience versus diagnosis denial

The acceptance process of illness in patients with AIDS could be glimpsed by verbal expressions and gestures of joy, contentment and motivation, which demonstrated the resilience of certain patients. Moreover, these individuals showed interest and positive disposition in relation to liabilities arising before the disease diagnosis, especially in relation to compliance with treatment and continuous monitoring of control examinations.

These patients also were concerned about preventing the spread of the virus, which was not observed in those who did not accept their diagnosis. This reality can also be embodied in a study conducted in a university hospital located in the city of Rio de Janeiro, the findings revealed that the process of acceptance is constituted of a positive aspect, since the lack of interest about the factors involving disease by the carrier of the virus can impair self-care and care for others, which allows the continuity of practices that may increase the chance of spread of HIV.5

Denying AIDS diagnosis may compromise the quality of life of patients and the protection of other persons due to lack of awareness in relation to breaking the chain of transmission. This awareness of those who accepted the diagnosis could be evidenced even during nursing care, which in most cases, these patients showed concern when some professionals did not wear the appropriate personal protective equipment (PPE), such procedure gloves to puncture vein. Sometimes, when the blood flowed after venous puncture or even during withdrawal of venipuncture, patients called the attention of the nursing staff in caring for contamination - facts that demonstrate respect and responsibility in controlling the disease for these patients.

Studies those focus on the active participation of the patient in conjunction with the multidisciplinary team in the context of their care and the care of others is essential to the success of the therapy.4 Therefore, some actions that can be used by nurses is dialogue, discussion and awareness of the individual on how to living with HIV/AIDS in their daily routine, considering the socioeconomic and cultural conditions. Nurses should seek to make the individual understand that the diagnosis of HIV/AIDS does not refer to the end of life and the exclusion of the same as a social being, but must make the individual understand that it will take a multidisciplinary network of support that will help you accomplish some care that previously were not required, as adherence to treatment, sex with condoms and periodic control examinations. Furthermore, stimulation of individual participation in his care, helps make the subject in the processes of health, and in the context of AIDS, does become responsible for his actions to himself and others.

Another feature evident, although to a lesser proportion of patients who accepted the diagnosis, was the need and interest in seeking enhance the knowledge about the disease, through participation in events and support groups those address the treatment, prevention, the transmission and psychological support in AIDS.

An important action that can be performed by the nursing staff is to encouraging resilience, which is to stimulating the patient's ability to adapting to situations arising from a variety of means adversity, by stimulating the exchange of experiences between these patients and demonstration of the appreciation of “being sick” during assistance. Encouraging patient participation in therapeutic support groups for AIDS may provide the individual to reframe the problem situation and may make you feel socially inserted.7

Another potential aspect mentioned in studies is that patients who realize the acceptance process of the disease, concomitant to therapeutic adherence, have a longer life. The process of “re-learn” to live with AIDS demands the participation of the individual as an active subject, because even if the disease has no cure it is necessary that patients are urged by health professionals to use to confront these attitudes, as palliative care, positive thinking and healthy life.5

English/Portuguese
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Emotional changes arising from the disease diagnosis

The presence of emotional disorders, especially negative feelings and mood disorders such as depression were a treat often found in most patients. Every day, we found the problem through verbalization of fear and guilt in relation to AIDS transmission to partners. In addition, we realized the apathy, isolation and sadness in which some certain patients were immersed.

Studies indicate that depression is the most common psychiatric disorder in patients suffering from AIDS and is associated, among other factors, to psychological impact of the diagnosis, early physical symptoms, course of the disease and the limitations it imposes and the complex psychosocial issues embraced. Furthermore, the physiological point of view can be directly associated with colonization of the central nervous system by HIV, opportunistic infections or intracranial tumors.5

The authors follow emphasizing that depression in patients with AIDS entails noncompliance, in addition to increased risk of suicide and particularly in HIV positive is common to the possibility of experiencing feelings of anger, guilt, self-pity and anxiety.8

Surveys show that, despite the negative impact of depression on the progression of HIV/AIDS and quality of life of people living with HIV/AIDS, the diagnosis of psychiatric diseases is not performed in 50-60% of cases. The fact may be related to difficulty in making the diagnosis of depression, considering the similarity of its clinical manifestations, with those occurring in HIV infection and AIDS, such as fatigue, decreased appetite, and change in sleep and loss weight. Adds to the difficulty of the individual in itself exacerbating its emotions with health professionals.9

Health professionals, especially nurses, should pay attention to this problem, assisting the staff in the prevention, diagnosis and treatment of psychological disorders in these individuals, aiming to promoting mental health of the same.9,10 The nurse must listen to the patient, let it express its anxieties and frustrations, establishing an affective link and empathy in order to identify vulnerable situations of depression and other mental disorders.

Repercussions of Social Order

Ignorance about the disease

Even with the diagnosis of AIDS for years, some patients showed weaknesses in knowledge about the disease, including forms of infection, prevention, treatment, among others. This is alarming because of the increased risk of spreading the virus, and impaired self-care. Some patients, especially those who deny the diagnosis, opting not to hold consultations and routine control and did not try to keep informed about the implications and complications that may trigger the disease in the body.

The literature emphasizes that the use of health education strategy for HIV-seropositive persons, directly reflected in the reduction of suffering, and humane approach and interpersonal relationships, assisting in the production of integrated care, ensure access to health services, operationalize prevention and rehabilitation with input supplies (condoms and antiretroviral drugs) as well as stimulates the daily movements that meet the principles of universality and completeness are fundamental to promoting health and quality of life.6

It is of extreme importance that nurses conduct health education practices at all levels of care, aimed at sharing information, considering both to the peculiarities of each patient presents. It is necessary also to understand the meaning of illness for each patient according to its reality.

Financial difficulties

It could show that in the social field with AIDS patients have many problems related to financial aspects. To paraphrase one of 'speech, it became evident that the disease is not complicated medication as many people speculate, because the cocktails are made possible by the government, it is difficult to live with the disease and all the other evils that it provides.

Some patients emphasized that expenditures are large due to the long period of hospitalization with it for caregiver expenses (because a family cannot always be present), given that the hospitalization period may last more than 30 days ago expenditure on food and water, in addition, there are difficulties of tests that are ordered and are not offered by the NHS and is still necessary to offset expenses of his family. Some reported living with a retirement and said the worst part is known that spending the little money earned is spent with an incurable disease and that at the end of the month will be insufficient money to subsidize all costs.

The research involving confronting the difficulties experienced by HIV patients, show that the professional aspect is one of the most important and troubling points in the lives of these individuals, this is because the absence and delays in the workplace because of AIDS
or opportunistic diseases, or the side effects caused by medications are some of the factors that generate a huge difficulty which such persons in their jobs. A possible reintegration into the labor market is also hampered because the stigma and social prejudice inhibit and hinder the professional interrelationship of these individuals with their other peers.

- **Family repercussions and social stigma**

In contemporary times, there is still a huge assumption that the individual affected by the human immunodeficiency virus will necessarily die. Part of society sees the individual as HIV drugs, homosexual or that person entered the world of prostitution, ie, it is believed that only people who fall in this context, will be an imminent risk to society. It is known that the profile of these patients has been changing in recent decades, but the social stigma and discrimination persist, it is therefore in this context that family support is needed.

Two facts are important to note: what commonly occurs is that on one side there is the patient affected by AIDS who generally avoids talking about the illness with family and when there is a comment or question, it will be quickly, soon, which demonstrates directly or indirectly dissatisfaction, fear, fear of being HIV positive. On the other hand, there is the family who also finds huge barriers to live with this reality, most of the time, creating isolated ways of providing assistance to the family affected by the disease.

It is known that one of the most tumultuous phases in patient-family relationship is to view the development of AIDS diagnosis, for this reason some families hide and deny the incident, as a way of escaping and running away from a situation that causes nuisance. However, it is important that the family plays an important role in integrating the patient's social environment in this way, the emotional and psychological support will be essential to encourage him to face adversity and move confidently disease before treatment and possible complications that may arise by chance.

The focus of nursing actions is to strengthen the ties of the individual to the family, since it is known that the relationship between patient and family, have an infinitely greater significance for their recovery than that established with any professional health team. Nurses should include the family in the care process, instructing them to information about needed for control and treatment of disease care, in addition, the study indicates that social support, including family, assists in reducing HIV risk behavior.

**CONCLUSION**

The performance of nursing in the care of patients with AIDS goes beyond promoting physical well-being, involves cognitive, affective-relational and technical-instrumental areas. Psychosocial support has become one of the most effective strategies to potentiate the response to treatment, therefore, in this study, the major psychosocial effects were identified in these patients and several actions were proposed to assist these individuals in coping with these demands.

The nurse acquires a challenging task, as it needs to have a holistic look, and most often deal with not only the patient, but also with family members in the hospital environment. Could also conclude that the demands of psychological and social order, reported in this study have a considerable impact on quality of life of individuals and should not be overlooked during nursing care.

It is noteworthy that through listening, the professional nursing can be attentive to the needs of users and then can form bonds that enhance the interpersonal relationship of these subjects. This process occurs when the trader shows open to the questions and concerns of patients and from this it can be seen the best forms of assistance and care and in parallel, activism and self-confidence of the patient can also be established for the treatment and self-care.

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