EXPERIENCE OF PATIENTS WITH HIV/AIDS AND THE INFLUENCE OF RELIGIOSITY/ESPIRITUALITY WHEN COPING THE DISEASE

VIVÊNCIA DE PACIENTES COM HIV/AIDS E A INFLUÊNCIA DA RELIGIOSIDADE/ESPIRITUALIDADE NO ENFRENTAMENTO DA DOENÇA

RESUMO

Objetivo: conhecer a vivência de pacientes com HIV/AIDS e a influência da religiosidade/espiritualidade no processo de enfrentamento da doença. Método: estudo qualitativo, descritivo, exploratório, realizado em um hospital público com 10 pacientes, utilizando a entrevista semi-estruturada. O estudo foi conduzido em uma área de emergência de um hospital público em João Pessoa (PB), Brasil. Resultados: ressalta a importância da religiosidade para os pacientes que se sentem aceitos, amados e cuidados, e que estas experiências influenciaram a mudança de vida e a percepção da doença. Conclusão: após a experiência de enfrentamento da doença, os pacientes tiveram uma nova percepção da doença, e a religiosidade influenciou na mudança de vida e na percepção da doença.
INTRODUCTION

The Acquired Immunodeficiency Syndrome (AIDS) represents one of the major health problems of the present time, due to its pandemic character and its severity. The synonymy of AIDS, a disease caused by the Human Immunodeficiency Virus (HIV), has as etiologic agent the HIV1 and HIV2 retroviruses of the Lentiviridae family, and by man reservoir.1

HIV evolves, causing severe dysfunction of the immune system, with the destruction of CD4 + T lymphocytes which are the main target cells of this virus. The quantity of these lymphocytes is an indispensable marker of this immunodeficiency and therefore, it is used to define the prognosis and to evaluate the indication of the beginning of antiretroviral treatment and to conclude the case of AIDS with epidemiological purposes.2

According to the World Health Organization3, there were 34 million confirmed cases of the disease worldwide by 2010, and there were 656,701 cases registered in Brazil by June 2012. Up to 2011, the number of cases was higher in males 397,662 (65.4%), with females with 210,538 (34.6%). However, there has been a greater balance of this percentage in recent years.

At present, the profile of the disease has changed, with the increase in cases among women (especially married women); children (by vertical transmission) and the elderly population4. However, with the advent of antiretrovirals, the life expectancy of the groups increased, as well as their quality of life. Nevertheless, living with the disease is not easy, deserving attention not only from Public Policies but also from society in general, which marginalized those who had the disease for so long. In this context, the support of family, friends, the church, among others, is important in coping with the disease, since it is a chronic disease.

Given the importance of expanding knowledge about how HIV/AIDS patients face the disease, a study was carried out with the following objectives: (1) to know the experience of patients with HIV/AIDS, and (2) to investigate the influence of religiosity/spirituality in the process of coping with the disease.

In the meantime, questions regarding the significance of life and reason for living, regardless of religious beliefs and practices, are considered spirituality, and religiosity refers to an individual who believes, follows, and practices a religion.3 4

METHOD

This is a qualitative, descriptive, exploratory study carried out in a public hospital specialized in the treatment of infectious diseases in the city of João Pessoa, Brazil, in August 2014, with 10 patients of both genders, who were hospitalized during the data collection period. The inclusion criteria were: to be over 18 years old and to have at least six months of diagnosis of the disease. The exclusion criteria were to be unable to answer the research questions or in isolation.

It is worth mentioning that ten patients were invited to meet the inclusion and exclusion criteria established in this study, and to satisfy the type of method used (qualitative), which does not consider the number of individuals investigated, but aims to understand the problem through the experience of the individual, working their values, attitudes of actions and their meanings, in which it is evidenced through the social context where the subject is inserted.5

As a data collection instrument, a semi-structured interview script was used, but the interview was not recorded because it was not allowed by the Institution, requiring that the researchers write down each word of the participants’ speeches in response to the following questions: When and how did you hear about the diagnosis? How did you feel when you discovered the disease? How do you feel today? What has changed in your life routine and relationships with family and friends? How do you perceive your illness? Does faith influence your way of facing the disease?

The research project was approved by the Research Ethics Committee of the Nova Esperança Nursing School under CAAA 35139314.60000.5179, ensuring respect for the ethical aspects recommended by Resolution CNS 466/12, Art. II, Ethical Aspects, which deals with human beings involved in research.6 In this context, participants received the color codename.

The analysis followed the steps foreseen in Content Analysis.7 Initially, a floating reading of the collected material was carried out, is then transformed into units of comprehension of the text (cores of sense), trying to identify empirical categories and subcategories. Then, there were reflections and interpretations about each category and subcategory presented, and the discussion of the data, using the literature pertinent to the theme.
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Today I carry this weight in a lighter way […] but when I’m ill my family talks a lot to me and tells me not to mess up, to kill myself. (Brown)

I take care of myself, I take the pills on time, and I feel like a normal human being like any other. Even without walking, I’m doing Business Administration and I feel very good. (White)

I feel that I have to think a lot about other people, be careful not to pass on to my family, to other people who approach me. (Green)

The support of family and friends in the face of the chronicity of HIV/AIDS is of the utmost importance because it allows the individual to feel loved, comforted, supported by this pain that is usually unexpected, abrupt. If you feel loved it is essential to continue living, fighting for life, as we observe in the speeches.

[...] I have the support of my relatives and they tell me to always take my medicine so I get well soon, so I can take care of myself. (Pink)

I joined another partner, he already knew that I had taken this and accepted me […]. (Black)

With my relatives and real friends, he has not changed, because they adore me, they love me without prejudice. (Lilac)

It changed my relationship with my family, they love me much more today than before, are very attentive to me at all, if I’m taking all the medications, right then, I feel very comfortable and welcomed by them. (Yellow)

♦ Category 3 - Broken ties, living with prejudice.

After the diagnosis was revealed, the interviewees began to suffer discrimination by the family and friends, generating, even more, sufferings and the abandonment of the treatment, as mentioned in the speeches below.

[...] I want to die because of the prejudice of the people with me, I am pointed in the street by the people […]. (Pink)

[...] my neighbor in front of me did not speak to me […], that partner left me. (Yellow)

The partner left me, he did not want to accept the disease so he left me […] some friends left […]. (Grey)

[...] the prejudice is very great, I try not to listen, therefore, I feel bad, it makes me sad, I have already abandoned the treatment twice […]. (Lilac)

Preconception. I’m sorry about people when they do, but I’d rather not talk to anyone, just who knows, it’s my sister. (White)

RESULTS

The participants of the study were seven males and three females, five were between 18 and 30 years old and four were more than 30; nine were single and one had consensual union; seven had completed elementary education, two completed high school, and one had incomplete higher education; eight had a family income of 1 to 2 minimum wages and two above two wages; four were from the Catholic religion, four from the Evangelical, and two said they had no religion.

The analysis of the discourses originated in the following categories and subcategories: Category 1 - Reactions to the diagnosis; Category 2 - Change of life; Category 3 - Broken ties, living with prejudice; Category 4 - A new perception of the disease and Category 5 - The influence of religiosity/spirituality.

♦ Category 1 - Reactions to the diagnosis

Respondents point to disbelief at the diagnosis of the disease and the desire to take life. Others report being able to hear another opinion and the support of family and friends, but fear and afraid permeating the first moments of the beginning of the experience with the certainty of AIDS, as reported below.

I went crazy, desperate and said that I did not have that disease, I did not accept it, I refused that diagnosis. (Green)

When I found out I was thinking bad things, I wanted to kill myself, but I got advice from friends and from the psychologist that this was not the best thing to do. (White)

I went to BR 101 to throw myself to die soon, I spent the whole afternoon, but the cars went away from me, so I went home and when I was trying to hang, my nephew Gabriel asked me what a game was, he saved my life. (Black)

I did not feel the floor because I was very healthy and now I was already HIV, so I was thinking bad things, to kill myself. (Rosy)

I was very sad because I would not be able to work in my profession anymore, I wanted to disappear, but I did not think about killing myself. (Yellow)

♦ Category 2 - Change of life

The speeches below point to a change in people’s lifestyles after being infected with the HIV virus. Moreover, the perception of family and faith in a Supreme Being was also referred, as we see in the speeches below.

I feel happy and I like doing my things, I’m very happy, I’m only sad when I have to go, but I think it’s for my good. (Rosy)

I feel like a normal person, I like to play, I’m a mess. (Blue)

Cruz DSM da, Cordeiro RS, Marques DKA et al.
The stigma of HIV in society is a reflection of ideas that accompany HIV/AIDS for decades, mistakenly referring to the so-called risk groups (drug addicts, prostitutes, homosexuals). Confronting the prejudice, especially of the family, of those who are significant and of the work colleagues is a very difficult task, sometimes leading the individual to the denial of the disease with consequent abandonment of the treatment, depression and even the attempt on life. Therefore, many restrict the group of people with whom you share the diagnosis.

♦ Category 4 - A new perception of the disease

It is observed in the speeches that some of the interviewees overcame the impact of the diagnosis, and had their feelings reformulated, starting to value life more, taking care of themselves more, loving the family more and being grateful to God for the new chance, that is, began to appreciate what had previously gone unnoticed.

I realize it calmly, but I do not drink and I do not smoke because it is not good for my health, then it can worsen my illness. (Grey) [...] my husband died "choir and bone" and today it is not like that anymore, I am fat and I take my medicines, in front of the people I say it is a medicine to avoid (pregnancy). (Blue)

Before I did not give much value to God, family nothing, only material goods, I always liked good things, I've traveled even outside Brazil. I have never given much value to faith or feelings, just things. But after all these things, illness, I think differently, [...] I feel sorry for dying because I would like to have: loved more, forgiven more, lived more with my family, watched my nieces grow, the sunset. (Lilac)

I think I have to thank God every day, think of my children who love me. Today I feel better, today I care about life, not before. (Green)

The perception of the disease will depend greatly on the support received from family and friends, and also on the individual's ability to overcome adversity.

♦ Category 5 - The influence of religiosity/spirituality

The following discourses highlight the importance of religiosity and faith in each participant's life. It was observed that regardless of religion, all professed the faith in a Supreme Being, which has helped them to accept better the new condition of life, to persevere in the treatment. They did not show any sense of revolt against God, nor did they attribute the guilt to the disease, but they thanked the new chance of life. Faith renewes hope, invigorates, strengthens and makes life easier.

I have great faith in God, Jesus. This faith helped me a lot because everything I ask for. When I discovered AIDS, I lived on drugs and I did not have this faith that has helped me [...] today, this faith helps me to face this disease and to live with people who have prejudice and help me to take so many drugs, because I know it's important, if it were not for it (faith) I would have died ... I get upset at times when I'm in pain, but I do not blame God but the person who "put it on me", but otherwise, I live well. (Grey)

I have faith in God, he helps me in everything. He is the Physician of the doctors. Today this faith lifted me from the bed, made me eat because I was in a room alone, that faith is in my thoughts. My God is Jesus, and He brings me hope for the whole day and I ask Him every day. (Black)

I have faith in God, Jesus, and I ask Him to change my contaminated blood with a new blood so that I can take care of my mother who lives in a room far from me, that faith helps me a lot. I have faith in God, Jesus Christ, that faith, confidence, makes me calmer, I listen to his words. I had bought a revolver to take my life, there I was on the sidewalk taking "one", there a child approached me and said: God would help me! And he gave me a confection, then left and sold the revolver and created more in God and increased my faith (Brown).

I have a lot of faith in God and in Our Lady of Desterro, this faith has helped me to free myself and to be free from drugs and to bear the burden that is this disease. It is very hard to stand alone, [...] people despise you and reject you. But this faith, trust in God has sustained me, God is Wonderful with me. (Rosi)

I believe in God, I go to the evangelical church, Catholic, white table, I have no problem with them, because everyone believes in one God. I am eclectic [...] if God has saved me from dying from CA, and even though I am alive with HIV, something he has special for me here on earth, and that is what sustains me that faith. [...] I do not have this, which I am passing as a punishment but as an ordeal, but I feel the love of God through the care of relatives with me. (Blue)

I have faith in God, because, without him, everything gets harder, heavier, people without God is nothing. This faith has helped me to face HIV because it has taken away pride, sadness, helped me live well, doing the right thing and not the wrong ones. I stopped babbling, I want to live well with my family because in the past I did not value and today this faith that strengthens me also opened my eyes. (Lilac)
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DISCUSSION

The discovery of having a chronic disease such as HIV/AIDS often generates feelings of anguish and despair at the possibility of the finitude of life in those still carrying the first idea that AIDS is synonymous with death.

The fear of diagnosing HIV/AIDS is understandable, due to the lack of knowledge about the disease by the general population, resulting from incomplete, misleading and sensationalistic information that is sometimes conveyed by the media, causing divergences and confusion of people about the disease.8,9 Thus, it is not uncommon for some to attempt suicide as a way of avoiding suffering and death that they believe accompany those who have the disease.8

When the impact of the diagnosis is overcome, a new perspective on life arises with the possibility of treatment. Since 1996, the Unified Health System (SUS) has provided universal and free access to medical care, and to all antiretrovirals, but adherence to treatment is still a challenge for health professionals.10 The efficacy of treatment is proven through levels of viral suspension, and the correct use of the therapy is necessary, that is, equal or greater than 95% of the prescribed doses. However, inappropriate use of these medications leads to viral resistance.11

In this study, patients adhered to treatment and lifestyle changes, with a choice of healthy habits, always motivated by family and faith in a Supreme Being. Overcoming the impact of diagnosis, many individuals adhere to the treatment and learn to live with the disease, seeking the pleasure of daily activities, healthy living and living with the family, new ways of coping with the disease.12

Sharing HIV/AIDS diagnosis is usually done carefully, with only the family and close friends, for fear of discrimination. Some of the study participants reported having been stigmatized by their partners, friends, and neighbors.

Stigma is experienced in different circles of society, depriving the individual who has the disease of enjoying his rights as a citizen, leading him to the fear of discovery by employers and co-workers.13,14 Thus, the lack of social support limits social coexistence and affective ties making it even more difficult to coexist with the disease.15

The members of the study referred to the importance of the family in coping with the disease. Family support helps in emotional stability and treatment, providing a good environment for the individual, with a consequent improvement in the quality of life.14

A study16 with seropositive women revealed that depending on the support network, revealing seropositivity to the family was positive because of the welcoming response. Regarding Spirituality/Religiosity, it was observed how faith in a Supreme Being, independent of religion, has strengthened the members of the study to persevere in the therapy. Because they feel loved by God, they feel motivated to continue fighting for life, standing firm in the face of adversity, with faith and hope for better days. Thus, their values were redefined, and their family and faith in God became prominent.

Belief in God, in a higher power, contributes positively to the patient and his family in dealing with the disease, regardless of the professed belief, for faith is independent of religion.17

Research18 conducted with individuals who contracted the HIV virus showed that the personal or collective relationship with a Supreme Being contributed to a better quality of life for these individuals, for the spiritual and social support received in the religious environment. Similar results were also observed in other studies19-20, which reported increased self-esteem, optimism, and satisfaction, as well as the reduction of alcoholic beverages by individuals who maintain a positive relationship with God and with religion.

In this sense, it is observed the need of health professionals to consider the importance of religiosity and spirituality as an aid to the therapy instituted for HIV/AIDS patients, in the planning of actions directed to this group, considering the benefits in clinical conditions, psychological, social, and spiritual challenges to the conflicts experienced by these individuals.21

CONCLUSION

The diagnosis of HIV/AIDS was experienced by the participants with a lot of pain, anguish, despair, and caused changes in lifestyle. The experience of illness is referred to as painful, especially in the face of people's prejudice, but resilience is also present, that is, overcoming difficulties and a new perception of life.

The family is seen as supportive, caring, and very important in this process of confrontation, leading them to rethink the value previously assigned to it. However, some family ties were broken, as it is still the...
diagnosis of HIV/AIDS difficult to accept and understand between the couple.

Religiosity/Spirituality, faith in a Supreme Being has influenced the experience of these patients with the disease, since they make them feel accepted, loved and cared, being such feelings directly related to a change in their perception about the disease, awakening the will to continue fighting for life, resulting in the improvement of health status by persistence in treatment, and also in relationships with others and with God.

It is suggested that health professionals seek to broaden their knowledge in the care of patients with HIV/AIDS, based on an expanded perception of their experiences, considering another need to be met, the spiritual, since this, in the process of coping with the disease.

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