Spirituality in the Life of People with HIV in Light of Neuman's Systems Model

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Abstract

Background: Since its discovery as the etiological agent of the Acquired Immune Deficiency Syndrome (AIDS), the Human Immunodeficiency Virus (HIV) has infected 75.7 million people worldwide. Due to the specific characteristics of the Brazilian population, spirituality, or spiritual well-being, is an important factor in the way individuals face the HIV/AIDS problematic and its consequences. This work seeks to understand the spirituality of people living with HIV in light of Neuman's Systems Model.

Methods and Finding: This is a qualitative, descriptive-exploratory research in light of the Systems Model proposed by Betty Neuman. Data collection took place between the months of March and August 2016 in an outpatient clinic of a university hospital located in the city of Recife, Pernambuco, Brazil, specialized in the treatment of patients with HIV/AIDS. Thirty people living with HIV participated in the study. The data were collected through a questionnaire and an interview with a semi-structured script and underwent categorical content analysis. The understanding of spirituality in living with HIV is presented in three categories: the discovery of the diagnosis and the initial reactions — stressors that affect the lines of defense; the spiritual and religious search — protection when stressors penetrate the lines of defense; and the influence of faith combined with ART in living with HIV — dynamic relationship of the variable spirituality with the other variables.

Conclusions: The applicability of the theory can provide important gains to the patient living with HIV/AIDS, generating a way to ensure

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the strengthening and establishment of lines of defense during their daily lives, and thus maintaining the balance of the patient's system, as well as the harmonic relationship between its variables and the environment.

Keywords

Nursing; HIV; Acquired Immunodeficiency Syndrome; Spirituality.

Introduction

Since its discovery as the etiological agent of the Acquired Immune Deficiency Syndrome (AIDS), the Human Immunodeficiency Virus (HIV) has infected 75.7 million people worldwide [1]. This serious public health problem has generated significant implications for people's lives over the years, and its confrontation has required incentives and resources from permanent public policies. In this context, Brazil has stood out as one of the pioneering countries in guaranteeing universal and free treatment [2].

It is considered that the treatment was the main factor associated with the decrease in mortality caused by AIDS, which promoted in the long run an increase of the population living with HIV[3], allowed the overcoming of strictly biomedical concerns and raised the concerns for the psychosocial and spiritual dimensions[4].

Due to the specific characteristics of the Brazilian population, it is considered that spirituality, or spiritual well-being, is an important factor in the way individuals face the HIV/AIDS problematic and its consequences [5]. A research study on coping strategies of people living with HIV (PLHIV) found that the most used strategy of these individuals is to search for religious/spiritual practices [6].

Another research on the topic of HIV and spirituality demonstrated a harmonic relationship between religious, spiritual and clinical itineraries in PLHIV [7]. Therefore, investigating this theme may provide

de subsidies for nursing care in care practice. The theoretical reference utilized in this study was the spiritual variable of Betty Neuman's Systems Model. The concepts addressed were patient/system, environment, health and nursing interventions [8].

In this sense, the objective of this research was to understand spirituality in PLHIV in light of Neuman's Systems Model.

Methods

This work was a qualitative, descriptive-exploratory research in light of the Systems Model proposed by Betty Neuman. This model is based on a flexible and holistic system containing five interactive variables in which human beings are embedded and related: physiological, psychological, sociocultural, developmental and spiritual. Thus, the focus was on the response of the patient/system to the various factors related to the environment and their potential for influence as stressors to the system and the nursing intervention through primary, secondary and tertiary prevention to maintain the patient's well-being [8].

Thus, the two main components of the model are the stressors and the reactions to them [8]. The stressors are forces of intra, inter and extra personal nature, which have the potential to break the stability of the system. Intrapersonal stressors are forces that occur within the individual. Interperso-

nal stressors occur between one or more individuals in their relationships. Extra personal stressors are forces that occur outside the system, arising from socio-cultural factors [9].

The patient/system consists of a dynamic open system of concentric circles progressing outward from the core or basic structure through the lines of resistance, normal line and flexible line of defense. The core or basic structure contains factors that are typical for human beings, the lines of resistance surround the core and protect it when stressors penetrate the lines of defense [10].

Therefore, it is considered that Neuman's Systems Model contributes as a theoretical support for the understanding of human responses when living with HIV/AIDS, which is subject to both positive and negative stressors, during the stages of the disease and the continuity of the drug treatment. However, the theorization will not be applied in this research, as we are only going to use the metaparadigms of the theory as conceptual bases, focusing on the spirituality variable.

Data collection took place between the months of March and August 2016 in an outpatient clinic specialized in treating patients with HIV/AIDS at a university hospital located in the city of Recife, Pernambuco, Brazil.

Thirty PLHIV participated in the study. The non-probability random sample was selected by a draw among patients who met the inclusion criteria: being monitored in outpatient clinics during the period of data collection, aged 18 years or older, of both sexes, time of reagent diagnosis for HIV equal to or greater than one year, who had control of TCD4 and viral load in the last 12 months. Those without clinical conditions to answer the questions orally or in writing were excluded.

The procedure for data collection began with the explanation of the research, signing of the Free and Informed Consent Form (FICF), and soon after the application of a questionnaire and interview with a semi-structured script. In the first step, the subjects

were instructed to fill out a questionnaire prepared for the research. This instrument aimed at the socioeconomic, demographic and clinical characterization of the PLHIV.

The questions that are part of the socio demographic scope of the questionnaire were elaborated based on the questionnaire used in a research carried out with the same type of population and applied with the objective of characterizing the subject. The sociodemographic questions were questions regarding gender, age, education, current marital status, professional status and questions regarding the year of knowledge of the diagnosis, the presence of symptoms and/or previous or current opportunistic infectious diseases, the use of antiretroviral medication and sexual orientation [11].

At the same meeting, the patient participated in an interview with the researcher, following a semi-structured script. The environment for data collection met the criteria of adequate light, comfort, and privacy. The interviews took place without interruptions and were recorded using a digital audio recorder and later transcribed for content analysis of the categorical type, according to the chronological poles: pre-analysis; exploration of the material and treatment of the results [10].

Thus, the significant units extracted from the interviews were grouped into categories, aiming to make a comparison with the model proposed by Betty Neuman [8], used as a theoretical reference in this research, resulting in the constitution of three categories presented and discussed based on the pertinent literature.

The study followed the recommendations of the Guidelines and Standards of Research involving Human Beings, according to Resolution number 466/2012, after obtaining opinion number: 1,448,859 from the Ethics and Research Committee of the University of Pernambuco, under CAAE: 53166816.5.0000.5192, approved on March 14, 2016.

To maintain the confidentiality of the participants, the following alphanumeric coding was used: Int., to designate the interviewees, followed by an Arabic numeral corresponding to the order in which the data was collected.

Results and Discussion

The participants of this research were characterized in order to understand the analysis of the results of the speeches. The intention was to identify the context of these patients and subsidize the understandings about spirituality and its influence on the treatment in their daily lives and interpersonal relationships.

Characterization of the study participants

When characterizing the participants it was identified that patients who were between 40 and 50 years old represented the highest percentage of participation (43.3%), followed by those between 50 and 60 years old (33.3%), and then those between 30 and 40 years old (13.3%). As far as gender is concerned, it was observed that 56.7% of the interviewees were male. As for education, it was noted that 50% of the patients had incomplete elementary school education.

About the religious options, we found a percentage of 43.3% Catholics, 30% Evangelicals, 10% Spiritualists, 10% as Christians, 3.3% practicing Candomblé, and 3.3% reported having no religion.

As for the forms of infection, it can be seen that most of the interviewees had the sexual route as the exposure category, with 73.3% of coverage in the study, mainly through heterosexual relationships. Among the interviewees, 20% reported not knowing the mode of contamination experienced.

After analyzing the clinical data, it can be seen that all research participants were using ART, but according to their statements, not all of them co-

rectly followed the guidelines, doses and schedules for medication administration. The number of hospitalizations among these patients ranged from one to 13 admissions, although most participants reported never having been hospitalized, and they were followed up in the researched reference unit.

When we compare the amounts of hospitalizations that each individual reported to their clinical TCD4 and viral load data, the relationship between the two variables is clear, since CD4 and viral load reflect in clinical and health terms the best parameters for clinical follow-up.

As for the time of reagent diagnosis, we observed patients ranging from one year to 35 years after the diagnosis was discovered, with an average of 10.4 years of living with the disease.

In this context, facing the disease and incorporating it into the process of living are issues that usually generate anxiety and suffering in the set of factors that can influence the daily lives of PLHIV. This understanding of spirituality in the PLHIV will be presented in the following three categories.

The discovery of the diagnosis and the initial reactions: stressors that affect the lines of defense

This category encompasses the feelings and reactions to receiving the news of a positive HIV diagnosis. The way and situations in which the individual received the result, as well as the knowledge of the diagnosis itself, generate several feelings in people's lives: fear, prejudice, judgments, fear of family rejection, and the difficulties that will be experienced in everyday life.

The discovery of the reagent diagnosis for HIV surprises many individuals who did not identify themselves as vulnerable, as can be identified in the following lines:

When I got the positive result I had no reaction... I didn't know what to think...I was in shock.

Int 3.

It was bad, sad, a surprise, I didn't expect it, I would never have expected such news.

Int 8.

It was horrible, I was devastated, stunned. For me it was a catastrophe.

Int 10.

Knowing the result was a shock, I got angry, I started vomiting, I lost weight.

Int 20.

It was the worst day of my life, I never imagined that I would catch this disease, I cried desperately, it took me a long time to accept it.

Int 29.

The following speeches demonstrate the clinical and psychological impacts after the discovery of the disease in the lives of individuals, showing the negative intrapersonal stressors that act on the flexible line of defense shaken in response to physiological and psychological changes in its structure, requiring the rebuilding of the system at the secondary level, since this level advocates the treatment of symptoms presented after the perception of the stressor, in an attempt to strengthen the internal lines of resistance.

It was a burden, worrying, I felt lost and alone.

Int 1.

It was horrible, I was devastated, stunned. For me it was a catastrophe.

Int 10.

It was a shock, it still is, I can't believe it. I couldn't get out of bed, I felt weak and unable to do anything.

Int 12.

I felt a lot, I got depressed, I went to a psychologist, it was difficult. I suffered and fought a lot to accept it, but now I am calm about it.

Int 16.

Receiving the result of a positive diagnosis for HIV arouses in individuals a variety of reactions, among them surprise, disappointment, sadness, despair, fear of the unknown and of what might happen. Some of the following lines characterize all the fear and anguish.

...I thought the world had ended for me.

Int 9.

It was a huge shock for me, very difficult, I kept thinking about the prejudice.

Int 15.

It was a very sad reaction, I was very desperate, I cried a lot and was very ashamed.

Int 18.

The lack of knowledge about the disease can interfere in the way the patient faces his or her diagnosis, and in this way they present themselves as intrapersonal aspects that influence the balance of the patient's system, and can overcome the lines of defense:

At first I didn't know what it meant...I thought it was no big deal...it was just something. Then I was very desperate, I cried a lot and was very ashamed.

Int 14.

I was very desperate, cried a lot and was very ashamed. Who discovered it was my ex-patron who referred my husband and got the news, and she had to tell me and take me to do the exam to know if I had it too. Later she told me and that was it, now my despair was because I was ashamed of her knowing that I had it. I denied it, said I didn't have it.

Int 6.

I denied it, I said I didn't have it, I was afraid for my children. They did tests, my wife and none of my children had the disease. It only happened to me... I was very upset.

Int 11.

It was and still is very difficult to live with this disease, people judge you, are afraid, they don't want to get close to you. I suffered a lot.

Int 29.

These reactions are strongly influenced by the beliefs and values cultivated by the individual, as well as by the social group to which he/she is inserted. Through the characterization performed in the study it was observed that the individuals interviewed were inserted in social groups that have income below the necessary.

The perception of not having control over the disease, with no cure, often still perceived as synonymous with death, can refer to religious content in the process of living with the disease, with the possibility of various influences on subjective well-being.

... I didn't know the disease...I saw a lot of thin people and I thought I was going to die.

Int 16.

Living with the disease triggers in most of the individuals interviewed the need to seek spiritual care, this variable acts in a positive way in the balance of the patient's system, and consequently acts

favorably in the intercession with the other variables of the individual's system. The statements below demonstrate spiritual care as an influence in the daily life of people who discovered the positive diagnosis of the disease.

It is not easy to have this disease, only those who live with it can understand what I feel, it is not easy at all. What we go through is very complicated.

Int 1.

We don't accept the disease, but we have to learn to live with it. Faith is like this, with the Holy Spirit of God in our lives that we have this support.

Int 2.

Many times we feel weak, and to learn to live with the disease, we have to learn with God's help.

Int 7.

[Spiritual beliefs] collaborate with living with the illness psychologically, I consider it to be a basis of support.

Int 11.

It is observed that in the aspects related to the stressors that influence post-discovery of the diagnosis of these individuals, the first reaction in most interviewees is a temporary state of shock, which can be understood as a series of stressful events, since they are characterized as stimuli that threaten the body, generating consequences and interfering with the lines of defense. When this feeling of fear ends, denial appears, revealed in most of the interviewees.

The period between HIV infection and the manifestation of AIDS can take several years, but despite the fact that the individual carrying the virus is often asymptomatic, he can present important disorders in the psychosocial sphere, from the moment he learns of his diagnosis [11].

The spiritual and religious quest: protection when stressors penetrate defense lines

This category describes the search of individuals for consolation and comfort through religiosity and spirituality.

In life we have to have faith in God, he can do anything, I believe in this a lot, I think this has helped me a lot.

Int 1.

My faith has power, because the Lord ((God)) is above everything and everyone, it is in Him that we find salvation, and it is only with Him that we find salvation. I have a lot of faith.

Int 3.

He gave me strength and courage, I couldn't even get out of bed. I arrived here with only the skeleton, I was recovering, thanks to God, today I am well.

Int 2.

If it weren't for God, I would have already thought about suicide. Alias, not thought, because I already thought, I would have done it. God gives me strength for everything.

Int 10.

... I even accepted [the illness], not at first, but later I got strength and went ahead

Int 16.

People don't believe in supreme and superior forces, but they make all the difference in our lives.

Int 29.

The finding of comfort and consolation in this difficult moment, among the participants of the study, refers to faith and salvation. What can be seen in the content of the speeches is that these

individuals have in their beliefs the basis for the strengthening of PLHIV.

Because God is comfort in difficult times. He ((God)) gives you strength when you think of giving up.

Int 24.

[...] only God in those hours provides comfort and consolation.

Int 6.

As far as the systems model of these patients is concerned, one can characterize this phenomenon as a way to maintain the stability and balance of the system of these patients, that is, a strengthening of the core defense lines, highlighting a distinction between spirituality and religiosity.

Having faith is what saved my life, not going to church and all that religious stuff, but believing in God.

Int 12.

The fact that it is a sexually transmitted disease can be understood as an aggravating factor of prejudice, a fact that can be found in religious groups, especially in congregations of Catholic or evangelical origin, because they have more rigid doctrines when compared to other religious beliefs in Brazil. This can be evidenced in the evaluation of the statements described below.

I was very afraid that people would find out, the church condemns many things

Int 3.

In church nobody knows about the disease, I am afraid of what the brothers will say, I prefer to keep it a secret.

Int 28.

Moreover, the strong presence of religion in the lives of the participants becomes an important factor in the search for spiritual care, as well as an aspect that generates strong influence for emotional imbalance in the patient's life, due to the fear of exclusion in this religious context.

The major concern according to Betty Neumans model[8] is in keeping the system stable by accurately assessing the effects and possible effects of environmental stressors and making necessary adjustments to the assistance in order to ensure an optimal level of well-being.

We realize that AIDS has been much more expressive from the psychic, social, cultural, political and economic point of view than the biological one, because the initial impact is the recognition of oneself as being one more participant in this difficult reality [12].

However, in the search for protection when stressors penetrate the lines of defense, one must consider the normative and dogmatic religious aspects that sometimes keep PLHIV away from religious institutions. A study conducted in the same region as the present study identified the nursing diagnoses impaired religiosity and spiritual suffering in PLHIV [4].

The influence of faith combined with ART in living with HIV: dynamic relationship of the spirituality variable with the other variables

This category covers the analysis of the interviewees' coexistence with the virus in their daily lives and the influence of faith in the daily context of PLHIV. From this moment and based on these aspects: living with the diagnosis of HIV/AIDS and its implications, living with the medication and its side effects, living with prejudice, that is, changing the main focus of the disease, no longer only the mode of transmission and aspects of the virus itself, but how to live and live after the diagnosis.

The consolidation of faith in this process is evident, observing the positive predominance that

strengthens the patient subject to the interference of various intra and extra personal stressors in the system. In this sense these negative stressors are related to the treatment experienced by individuals and also to the search for faith [13].

The drug treatment presents itself in the system in a positive and negative way, as it contributes to the maintenance of balance lines and clinical improvement of the patient, as well as generates discomfort due to its drug and psychological effects on the patient, considering that the side effects of the medication bring discomfort and setbacks for these patients using ARV [14], as can be observed in the following speech, highlight the difficulties encountered in relation to the side reactions and discomforts of taking HAART.

...Take a lot of medicines, you feel very bad with them, that's when I look for strength in Jesus to continue.

Int 30.

On a positive note, we find the report of one of the participants who considers the combination of his spirituality and the treatment with ARV to be a resultant factor for his well-being:

I weighed up to 35 kg and got well by my spirituality along with medicine.

Int 14.

The good adherence to treatment reported by most patients is certainly an important factor for the maintenance of the good health conditions referred. It is necessary to ponder, however, that the participants were in outpatient clinical follow-up in reference health services, which may have influenced this favorable panorama, not necessarily reflecting the characterization of the epidemic in the state of Pernambuco, Brazil.

It gave me strength, and it still gives me strength. It is not easy to have this disease, only those who live with it can understand what I feel, it is not easy at all.

Int 2.

It is not the physical healing, it is the spiritual healing. Only God sustains me, and the doctors who are God's instruments, spirituality saves.

Int 21.

[...] I put my faith, if I did not believe, if I did not have the faith that I was going to take the medicine that I was going to get well I would not be here today.

Int 27.

Spiritual practices alter brain neurochemistry and offer a sense of peace, security, and happiness, reducing anxiety, stress, and depression. The religious experience, by inspiring thoughts of optimism and hope, as well as positive expectations, for some researchers works as a placebo [15-16]. Spiritual care reaches across the normal line of defense and promotes stabilization and reconstitution of the patient's system, promoting the outcome of spiritual well-being that is achieved when the client/patient expresses meaning and purpose in life, re-establishes relationships, and resumes practices of a belief system [8].

In order to reach this effect, Neuman's model proposes primary prevention, which acts as an intervention to minimize stressors and strengthen the flexible line of defense to retain and promote the level of well-being, i.e., spiritual care in primary prevention basically involves identification of the client/patient system dealing with strengths and support of health promotion activities, education, acting strategies and early guidance [17].

Spiritual care in secondary prevention as an intervention level involves collaboration between the pa-

tient and nurse to set goals that alleviate symptoms of maturational or situational stressors and prevent penetration of the flexible line of defense, normal line of defense, and lines of resistance. The realization of wellness can be the result of interventions such as: listening, being empathic, touching, sharing with others, adding interventions with the use of music, as well as offering prayers, reading religious literature, and assisting with rituals [8].

Whereas tertiary prevention is the maintenance of wellness, which begins when treatment of stressors results in the path to stability. Spiritual care interventions that support existing strengths and conserve the energy of the client/patient system include facilitative adaptation and education about spiritual resources to maintain the patient's lines of resilience and lines of defense during stabilization and reconstitution. These interventions are directed toward the goal of maintaining optimal wellness [8].

Spiritual care interventions are individualized to protect basic structure, alleviate stressors, and initiate reconstitution. The ultimate goal is to have the client/patient recognize and mobilize personal spiritual resources that maintain stability and strengthen other interacting variables in the client/patient system. In the event that spiritual care interventions are not employed, the effectiveness of lines of resistance may be reduced, leading to energy depletion or death [8].

Conclusion

Nursing stands out as a profession of important proximity and interaction with the patient and, therefore, becomes responsible for a holistic look that contemplates, in the process of care, the biological, mental, emotional, and spiritual dimensions of the human being. Because of this, the understanding of themes such as spirituality presents itself as a fundamental factor for the provision of nursing care, from health promotion to rehabilitation.

The results of this study demonstrate that providing more opportunities to discuss the role of spirituality, from the beginning of the training of nursing professionals and in continuing education activities, can contribute to the rescue of the essence of integral care.

It is also observed that the greater or lesser involvement of nurses with the spirituality and religiosity of those who are under their care seems to be favored by scenarios in which situations of fragility of patients are evidenced. The applicability of Betty Neuman's systems theory can provide important gains to the patient who lives with HIV/AIDS, generating a way to guarantee the strengthening and establishment of the lines of defense during his/her daily life, and thus maintaining the balance of the patient's system, as well as the harmonic relationship between its variables and the environment. It is up to the nurse to apply the preventions of the spirituality variable according to the individual needs of each patient, in order to be in harmony with the other variables of the system.

Future studies that contemplate the perspectives on religiosity and spirituality and their applicability to care as well as their influences may contribute to expand the knowledge on this theme.

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Competing and conflicting Interests

There are no conflicts of interest.

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