

# Impaired religiosity and spiritual distress in people living with HIV/AIDS

*Religiosidade prejudicada e sofrimento espiritual em pessoas vivendo com HIV/aids*

*Religiosidad deteriorado y espiritual sufrimiento en personas con VIH/sida*



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## ABSTRACT

**Objective:** To verify the inference of Nursing Diagnoses, Impaired religiosity and Spiritual distress in people living with HIV/AIDS.

**Methods:** This is a cross-sectional study with a quantitative approach, performed in a specialized Service Center of Recife, Pernambuco, from June to November 2015. The results related to 52 people living with HIV/AIDS and that were interviewed were analyzed by three nurse judges.

**Results:** Spiritual distress was estimated at 73.1% (38), Impaired religiosity at 36.5% (19), with an average number of defining characteristics of  $3.88 \pm 2.05$  and  $2.55 \pm 0.69$ . The main defining characteristic for Impaired religiosity was: "reports a need to reconnect with previous beliefs" (92.3%); and for Spiritual distress, it was: "Expresses a lack of purpose in life/expresses lack of meaning in life" (86.5%).

**Conclusions:** The results point to the need to consider the religious-spiritual dimension in care protocols and research in nursing.

**Keywords:** Spirituality HIV. Nursing diagnosis.

## RESUMO

**Objetivo:** Verificar a inferência dos Diagnósticos de Enfermagem, Religiosidade prejudicada e Sofrimento espiritual em pessoas vivendo com HIV/AIDS.

**Métodos:** Trata-se de um estudo transversal, com abordagem quantitativa, realizado em um Serviço de Assistência Especializada de Recife, Pernambuco, de junho a novembro de 2015. Os resultados relacionados às 52 pessoas vivendo com HIV/AIDS entrevistadas foram analisados por três juízes enfermeiros.

**Resultados:** Estimou-se em 73,1% (38) a incidência de Sofrimento espiritual, 36,5% (19) de Religiosidade prejudicada, com número médio de características definidoras de  $3,88 \pm 2,05$  e  $2,55 \pm 0,69$ . A principal característica definidora para a Religiosidade prejudicada foi: "relata necessidade de reconectar-se com crenças anteriores" (92,3%); e para Sofrimento espiritual: "expressa falta de finalidade na vida/expressa falta de significado na vida" (86,5%).

**Conclusões:** Os resultados apontam para a necessidade de considerar a dimensão religiosa-espiritual nos protocolos assistenciais e de pesquisa em enfermagem.

**Palavras-chave:** Espiritualidade. HIV. Diagnóstico de enfermagem.

## RESUMEN

**Objetivo:** Comprobar la inferencia de diagnósticos de enfermería, deterioro religiosidad y sufrimiento espiritual de personas con VIH/SIDA.

**Métodos:** Se trata de un estudio transversal, cuantitativo, realizado en un servicio de atención especializada de Recife, Pernambuco, de junio a noviembre de 2015. Los resultados de 52 encuestados fueron analizados por tres jueces enfermeras.

**Resultados:** Se estimó en un 73,1% (38) la incidencia de sufrimiento espiritual, el 36,5% (19) de la Religiosidad con deficiencias, con un promedio características definitorias de  $3,88 \pm 2,05$  y  $2,55 \pm 0,69$ . La principal características definitorias de Religiosidad alterada: los informes tienen que volver a conectar con creencias anteriores (92,3%); y Sufrimiento espiritual: expresión de la falta de propósito en la vida/falta de sentido de la vida (86,5%).

**Conclusiones:** Los resultados apuntan a la necesidad de considerar la dimensión religiosa-espiritual en los protocolos de atención y la investigación en enfermería.

**Palabras clave:** Espiritualidad. VIH. Diagnóstico de enfermería.

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## ■ INTRODUCTION

Antiretroviral therapy (ART) contributed for AIDS to be considered a chronic disease and thus increased the survival of people living with HIV/AIDS (PLWHA), improving the quality of life<sup>(1-2)</sup>.

However, it is worth examining the fact that these people need continuous and comprehensive care, in addition to the commitment to self-care. This is a challenge for patients, since living with the disease leads to changes in their daily lives and the fact that AIDS is still marked by prejudice and social stigma<sup>(2)</sup>.

To foster the patient and systematize continuous care, it is necessary, among other aspects, to consider the impact that living with a chronic and stigmatizing disease has in the life and mental health of these people. In this sense, there is a need for professional, social, family and religious-spiritual support<sup>(3-5)</sup>.

Religiosity has been considered an important tool in coping strategies of new situations that are imposed on the lives of people living with HIV/AIDS. Patients who claimed to have "no religion", but said they believed in God, sought Him as a source of strength, comfort and hope in the face of HIV<sup>(5-6)</sup>. Similarly, the disease can also bring a negative impact to the lived experience/religious-spiritual experience<sup>(6)</sup>.

Considering the need of health professionals to provide comprehensive and individualized care, in which religion should be inserted, it is necessary to understand the expressions and positive or negative relationships in experiencing the illness, trying to accommodate the anxieties of these users and assist them in their search for autonomy<sup>(5)</sup>.

The taxonomy for Nursing Diagnoses (ND) provides diagnoses that include this holistic approach of patients living with chronic diseases. The taxonomy in force, proposed by the North American Nursing Diagnosis Association – NANDA II in Domain 10: Life Principles that brings the following ND, with their respective concepts<sup>(7)</sup>: Impaired Religiosity: impaired ability to exercise reliance on beliefs and/or participate in rituals of a particular religious faith; spiritual distress, impaired ability to experience and integrate meaning and purpose to life through a connection with yourself, with others, with art, music, literature, nature and/or a greater being.

The first diagnosis addresses the issue of religion, beliefs or customs, the religious habits of patients, while the second approaches to spirituality itself, related to a concept of transcendence that may or not be experienced/related to a religious experience. In this context, the following question arose: what is the incidence of Impaired

Religiosity and Spiritual distress NDs in people living with HIV/AIDS, and what are the main defining characteristics for these diagnoses?

This study aims to verify the inference of Nursing Diagnoses, Impaired religiosity and Spiritual distress in people living with HIV/AIDS.

## ■ METHODS

This is a cross-sectional study with a quantitative approach, performed in the University Hospital's Specialized Health Care Center (SAE) of Recife, Pernambuco, a reference in the treatment of HIV/AIDS. The study was conducted between June and November 2015.

Data from the following matrix project was used for this study: "Religious and spiritual coping in people living with HIV/AIDS", which held a socio-demographic and clinical data survey, and the application of a validated scale of religious and spiritual coping (SRC) in a sample of 52 PLWHA of both sexes, diagnosed with HIV for at least one year, 18 years of age or older and who did not have cognitive impairment or neurological disorders that prevented participation in the interview.

The SRC scale is an instrument adapted and validated for the Brazilian population based on a North American scale. The instrument consists of 87 items covering issues relating to religion and spirituality to cope with stressful situations. When applying the instrument, participants were instructed to answer the questions thinking specifically of the situation of the disease (HIV/AIDS)<sup>(8)</sup>.

The answers were given per a Likert type scale of five points ranging from 1 (not at all) to 5 (very much). The correlation of the data was performed according to the criteria proposed by the authors of the scale<sup>(8)</sup> which allows the verification of the following scores: Positive SRC: indicates the level of positive religious and spiritual coping practiced by the person assessed, and is considered by the average of 66 issues of the scale's positive dimension; Negative SRC: indicates the level of negative religious and spiritual coping practiced by the participant, being considered from the average of 21 issues of the scale's negative dimension; Total SRC: indicates the total amount of religious and spiritual coping strategies used, established by the average between the positive SRC index and the average of inverted responses for the 21 issues of negative CRE<sup>(8)</sup>.

The parameters used to analyze the mean SRC values regarding their use by the respondent were no or insignificant: 1.00 to 1.50; low: 1.51 to 2.50; medium: 2.51 to 3.50; high: 3.51 to 4.50 and very high: 4.51 to 5.00. The scale also allows eight positive religious and spiritual coping factors,

and four negative coping factors to be evaluated, although they were not an object of study in this research.

The study took place in three stages: 1) Use of matrix project data that consisted of sociodemographic and clinical variables and the SRC scale; 2) Correlation between the SRC scale and the defining characteristics established by the judges; and 3) Statistical analysis and inference of the characteristics that define the NDs of *Impaired Religiosity* and *Spiritual distress*.

The correlation between the SRC scale and the defining characteristics established by the judges was held with the participation of three specialized nurses, with master's degrees in nursing and research experience with nursing diagnoses, HIV/AIDS and research in Health and Spirituality. It was requested that the judges (nurses) connect the defining characteristics of *Impaired Religiosity* and *Spiritual distress* NDs to the items of the Religiosity-Spiritual Coping scale that express the same content, idea or concept. Divergences were crossed and the judges were again consulted about the possibility of improving the first connection. Finally, the different items remained when cited by at least two of the judges.

Data were analyzed with descriptive and inferential statistics resources, using the SPSS 20.0 software. For the defining characteristic to be considered present, the medium of values for the respective items of each was calculated, considering those with an above average score as a characteristic present in patients. This means that all patients with an above average answer compared to the rest of the sample would be considered as having the defining characteristics. Regarding NDs in patients, the ND were considered present in those who presented three or more defining characteristics. The reliability in the use of the scale was assessed by Cronbach's alpha, being considered as significant internal consistency (total CRE,  $\alpha = 0.86$ ). The Pearson correlation test was used to evaluate the association between continuous variables.

All ethical principles of Resolution No. 466/2012 of the National Health Council were respected and the research protocol was approved by the Research Ethics Committee of the hospital complex – Hospital Universitário Oswaldo Cruz/Pronto-Socorro Cardiológico de Pernambuco, under the Certificate of Presentation for Ethics Assessment (CAAE) No 43056315.5.0000.5192 and opinion No. 1.007.864. It was requested that a Free and Informed Consent Form be signed by the research participants, with the guarantee of preserving their anonymity and maintaining the confidentiality of the information provided during all phases of the research.

## ■ RESULTS

Most patients were male (35; 67.3%) with a mean age of  $45.04 \pm 9.43$  years old, single or without partners (75.0%), from the metropolitan area of Recife (23; 44.2%) and the capital (21; 40.4%), retired (19; 36.5%) or employed (17; 32.7%), with an income of up to 1.5 minimum wages (36; 69.2%) and without children (23; 44.2%). The main religious affiliation was to the Catholic Church (22; 42.3%) followed by the Protestant Church (19; 36.5%), with only one atheist (1.9%).

Patients had lived with the diagnosis for an average of  $9.92 \pm 6.34$  years, with  $8.47 \pm 5.72$  years of antiretroviral therapy use. The average of previous hospitalizations was  $1.29 \pm 1.91$  admissions. Regarding comorbidities, 19 patients (36.55%) had at least one and 18 (34.62%) had two or more. Fifteen patients had no comorbidities/opportunistic infections (28.85%).

Regarding the SRC, it was demonstrated that the Positive SRC was used in high mean scores ( $3.66 \pm 0.88$ ) and Negative SRC had low usage ( $2.12 \pm 0.74$ ). In total, the use of SRC was high ( $3.77 \pm 0.74$ ), with a predominance of Positive SRC (ratio PSRC/NSRC =  $0.65 \pm 0.46$ ).

The inference of nursing diagnoses was estimated considering the combination of three or more defining characteristics. Thus, it was estimated that 73.1% (38) of the patients had *spiritual distress*, while 36.5% (19) had *Impaired religiosity*. The average values of the number of defining characteristics presented were  $3.88 \pm 2.05$  and  $2.55 \pm 0.69$ , respectively. Ten patients (19.2%) had both diagnoses (Table 1).

In the correlation analysis, there was no statistical significance between the number of defining characteristics for *Spiritual distress* with the diagnostic time variables, antiretroviral therapy period and previous hospitalizations. The same analysis for the number of *Impaired Religiosity* DC (defining characteristics) of the ND showed a weak association with the diagnosis ( $p = 0.039$ ) and therapy ( $p = 0.048$ ) periods.

The main defining characteristics for *Impaired religiosity* and *Spiritual distress*, are shown in Table 2.

## ■ DISCUSSION

The use of nursing diagnoses still represents a challenge in care practice, specifically those of a more subjective character, considered of a lower priority. Possible explanations are the lack of training for the use of taxonomies in academia<sup>(9-10)</sup> and the need for more studies to consider the psycho – spiritual dimension of patients in general and, in particular, those living with HIV/AIDS<sup>(11)</sup>.

**Table 1** – Correlations between the items of the Religious and Spiritual Coping scale with the defining characteristics in the opinion of experts. Recife-Pernambuco, 2015

ND: Impaired religiosity		SRC Scale Items
<b>Defining Characteristics</b>		
Questions patterns of religious beliefs		6, 9, 50, 51, 69
Reports spiritual distress for separation from a religious community		41
Reports the need to reconnect with former customs		8, 60, 63, 74, 75, 87
Reports the need to reconnect with former beliefs		8, 13, 26
ND: Spiritual distress		SRC Scale Items
<b>Defining Characteristics</b>		
Refusal to integrate with spiritual leaders		15
Expresses anger with a greater being		4, 83
Expresses feelings of abandonment		32, 41, 84
Fault		23, 56, 59, 78
Expresses lack of self-forgiveness		23, 56, 59
Report being separated from their support system		18, 41, 73
Requests to talk to a religious leader		12
Expresses lack of purpose in life		17
Expresses lack of meaning in life		30, 38
Rage		4

Source: Research data, 2015.

The presence of spiritual distress in a significant portion of respondents was demonstrated through this study, however, it is not observed to the same extent as impaired religiosity, in addition to the observation of a predominantly positive SRC. In the planning of care for these patients, religiosity should be considered as a source of faith and strength, since it can contribute to improve the spiritual distress experienced by these patients<sup>(12)</sup>. It is important to consider that the most prevalent DC for the ND “spiritual distress” was the lack of meaning and purpose in life, lack of self-forgiveness and guilt. For these NDs, it is relevant for the Nursing team to consider the spiritual dimensions as a source of aid in assisting and promoting health.

Religiosity and spirituality represent support in accepting the diagnosis, thus providing a more positive attitude in fighting the disease, an issue of the utmost importance for people living with chronic diseases<sup>(5)</sup>. It is necessary for the Nursing staff to be trained to use the diagnostics related to religiosity and spirituality thus, qualifying the assistance provided by the Nursing team.

It is observed that, in addition to the need to acquire the ability to work with ND involving religiosity, it is important to establish a professional connection to start the ap-

proach in this context. It is noteworthy, however, that there is no standard way of working with religiosity and spirituality in health, that besides the importance of establishment of a patient-professional relationship and professional competencies and skills, one should also consider the personal beliefs of the professional and the patient<sup>(5)</sup>.

There are validated scales to assess religiosity and spirituality, in their various aspects, which has been used in research<sup>(12)</sup>. In this study, a validated scale was used to support the use of nursing diagnoses, in collaboration with the defining characteristics also validated. The results indicate this possibility that should be considered in Nursing education, and can be used for quality and recognition of Nursing as science.

Regarding the use of the Religious-Spiritual Coping scale, it was observed that positive SRC was used in high average scores, the negative SRC had low use, with a predominance of positive SRC. Based on the study findings, it is possible to say that religiosity/spirituality is relevant in addressing HIV, since the scores of all religious and spiritual coping were high. Furthermore, positive coping has been used more than the negative coping, which corroborates the results obtained in other studies<sup>(13-16)</sup>.

**Table 2** – Estimated frequency of defining characteristics. Recife-Pernambuco, 2015

ND: Impaired religiosity		n (%)
<b>Defining Characteristics</b>		
Reports the need to reconnect with former beliefs		48(92.3)
Reports the need to reconnect with former customs		44(84.6)
Questions patterns of religious beliefs		11(21.2)
Reports spiritual distress for separation from a religious community		4(7.7)
ND: Spiritual distress		n (%)
<b>Defining Characteristics</b>		
Expresses lack of purpose in life		45(86.5)
Expresses lack of meaning in life		45(86.5)
Expresses lack of self-forgiveness		29(55.8)
Fault		27(51.9)
Expresses feelings of abandonment		14(26.9)
Requests to talk to a religious leader		14(26.9)
Refusal to integrate with spiritual leaders		8(15.4)
Rage		8(15.4)
Expresses anger with a greater being		7(13.5)
Report being separated from their support system		5(9.6)

Source: Research data, 2015.

The *spiritual distress* ND showed to be high and the frequency of the defining characteristics depicts that said diagnosis relates more to transcendence issues and meaning than to practices and beliefs. Mainly, two dimensions were expressed directly, related to negative coping: lack of purpose or meaning in life and the relation between guilt and self-forgiveness. According to what was found in this study, respondents have difficulties in planning their lives after receiving the HIV diagnosis, and perceive changes in lifestyle. They also report feelings of abandonment, hopelessness, guilt, anger, fear and uncertainty of the future.

A similar study held on a national level with 146 people living with HIV/AIDS showed that 87% had psychospiritual needs, particularly religious, affected by the interaction of the disease, with no significant impact on the decline in the quality of life in any domain<sup>(17)</sup>.

The number of patients who had an *Impaired Religiosity* ND show positivity, since respondents consider religiosity important in coping with the disease and lifestyle change. The distribution of key defining characteristics for the *Impaired Religiosity* diagnosis was mainly related to the beliefs, customs and practices that patients recognize as important and demonstrated the intention to resume them or enforce them. For this diagnosis, most related items were part

of the positive coping factors, allowing the understanding that for patients, religiosity is used as a source of faith, comfort and hope for personal empowerment.

For those who declare they belong to a religion, the emphasis on self-acceptance of the disease and the new conditions it imposes can be seen. In this sense, religion helps in fighting the disease and the search for the meaning of life in the disease process, which corroborates what was found in another study<sup>(5)</sup>. Some religious denominations also bring concepts in their doctrines that reinforce the widespread prejudice and stigma in society. The patient speeches analyzed, with some affiliations, showed a larger and more clearly expressed sense of guilt and difficulty in self-forgiveness<sup>(5)</sup>.

In a national publication, when evaluating 90 people with HIV, it was found that religiosity had a positive and significant connection with quality of life, especially in the psychological, social and environmental fields. Of these patients, most called themselves "Religious" (33%) and "Very religious" (30%)<sup>(14)</sup>.

The study showed that respondents showed a lack of purpose/meaning in life, expressed feelings of guilt and abandonment, showed anger towards the diagnosis, 26.9% recognized the need to speak to a religious leader.

The diagnosis of HIV implies physiological, social and especially psychological changes for the individual, since in addition to the social stigma, there is a lifestyle change because of treatment with antiretroviral drugs, which often comes with side effects, as well as problems that arise related to mental health, related to guilt and anger for not having prevented themselves, an uncertainty in the future and the fear of rejection, abandonment and death.

In a longitudinal study that followed 177 people with HIV for 10 years, it was revealed that before potentially traumatic situations where adaptation is difficult, such as approaching death, suffering from the stigma of the disease, poverty and limitations, most patients used spiritual coping, of these, half experienced comfort, empowerment, growth, transformation and gratitude and a third found meaning for the disease in their life and underwent a process of resignification<sup>(15)</sup>. Another study with a sample of 465 people with HIV/AIDS, found similar results, reinforcing the relevance of religion to life with the stigma and the disease<sup>(16)</sup>.

Conversely, the negative religious and spiritual coping related to crises and nursing diagnoses studied was made evident in direct relation with higher levels of depression and lower levels of quality of life in a significant sample of PLWHA<sup>(17)</sup>.

Regarding the systematization of nursing care, data show a low incidence or few citations related to the theme "religiosity and spirituality" in sexually transmitted diseases, HIV and AIDS<sup>(11)</sup>. The fact of not being considered a priority does not mean that diagnoses such as those that make up the area 10 of NANDA Taxonomy II – Life principles are not important.

In a national publication that investigated 30 patients with HIV/AIDS to identify key ND applicable through the Horta conceptual model, found only the ND *Readiness for enhanced spiritual well being*, and applied to three patients<sup>(18)</sup>. There is no way to assert that these values are due to the bias of the interviewer or instrument failure. However, the data presented portray that there is an underreported reality and that nursing professionals should take greater interest in the subject. The application of nursing diagnoses related to spirituality and religiosity provide the patient with more qualified assistance and help in the reflection on the importance of religiosity and spirituality in coping with and accepting the disease.

## ■ CONCLUSION

Religiosity and spirituality are dimensions that must be considered in all nursing actions in the healthcare field, research and extension, enabling the construction of knowledge.

With this study, it was observed that validated scales can provide support for the identification of nursing diagnoses and consequently, the development of goals and actions in the health care context.

The high incidence of *Spiritual distress* and *Impaired religiosity* found shows that religious and spiritual support can help PLWHA in fighting the disease and the social stigma, which reinforces that the use of nursing diagnoses and interventions can contribute to the improvement of care provided to these patients.

To acknowledge the importance of religiosity/spirituality can help professional nurses to create a greater bond of trust with the patient, enabling religious coping strategies to be established.

The present study presented a certain degree of difficulty in collecting data as its limitation, because of the Coping Religious-Spiritual Scale's extension and the fact that it was applied in the SAE while patients were waiting for their specialist appointments, in addition to the lack of a nursing care plan provided by the nursing staff, a fact that shows the need for research that broadens the object of study, focusing on the systematization of nursing care (SAE) for patients with HIV/AIDS.

The results discussed here bring contributions to a qualified care practice with a more efficient service considering the Nursing diagnoses related to impaired religious and spiritual distress, which must also be considered in Nursing education.

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