

INFLUENCE OF SPIRITUALITY, RELIGION AND BELIEFS IN THE QUALITY OF LIFE OF PEOPLE WITH SPINAL CORD INJURY

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ABSTRACT: The objective was to evaluate the influence of spirituality, religion and personal beliefs in the quality of life of people with spinal cord injury. This is a quantitative and exploratory longitudinal cross-sectional study. Data were collected from 49 people with spinal cord injury in two steps, in the hospital and at home, by applying the Quality of Life assessment tool - Spirituality, Religion and Personal Beliefs (WHOQOL-SRPB). Exploratory analyses were performed by using univariate frequency distributions and descriptive measures; validation of internal consistency; and by calculating the dimensions of the scale scores. The results show that the dimensions related to spirituality, religion and personal beliefs patients adopted as strategies to improve their quality of life in this research were confirmed by the high scores in the WHOQOL SRPB areas in both phases; there were differences only in the dimensions Sense of life and Spiritual strength. It is hoped that this study can highlight the importance of spiritual and emotional care.

DESCRIPTORS: Spinal cord injuries. Spirituality. Religion. Quality of life. Nursing.

INFLUÊNCIA DA ESPIRITUALIDADE, RELIGIÃO E CRENÇAS NA QUALIDADE DE VIDA DE PESSOAS COM LESÃO MEDULAR

RESUMO: Objetivou-se avaliar a influência da espiritualidade, religiosidade e crenças pessoais na qualidade de vida de pessoas com lesão medular. Estudo de abordagem quantitativa, exploratória de corte longitudinal. A coleta de dados de 49 pessoas com lesão medular ocorreu em duas fases, no hospital e no domicílio, e foi conduzida por meio da aplicação do instrumento de Avaliação de Qualidade de Vida - Espiritualidade, Religião e Crenças Pessoais (WHOQOL-SRPB). Foram realizadas análises exploratórias mediante uso de distribuições de frequências univariadas e medidas descritivas; validação da consistência interna e cálculo dos escores das dimensões da escala. Os resultados demonstraram que as dimensões relacionadas à espiritualidade, religiosidade e crenças pessoais, adotadas pelos pacientes como estratégias para melhoria da sua qualidade de vida, confirmaram-se a partir dos altos escores obtidos nos domínios do WHOQOL-SRPB em ambas as fases; houve diferenças apenas nas dimensões Sentido da vida e Força espiritual. Espera-se que este estudo possa despertar para a relevância do cuidado espiritual e emocional.

DESCRIPTORIOS: Traumatismos da medula espinhal. Espiritualidade. Religião. Qualidade de vida. Enfermagem.

INFLUENCIA DE LA ESPIRITUALIDAD, RELIGIÓN Y CREENCIAS EN LA CALIDAD DE VIDA DE LAS PERSONAS CON LESIÓN MEDULAR

RESUMEN: El objetivo fue evaluar la influencia de la espiritualidad, la religión y las creencias personales de la calidad de vida de las personas con lesión medular. Se trata de un estudio cuantitativo, exploratorio de corte longitudinal. La recolección de datos se dio con 49 personas con lesión medular en dos fases: en el hospital y en el hogar, y se llevó a cabo mediante la aplicación del instrumento de Calidad de Vida - Espiritualidad, Religión y Creencias personales - WHOQOL-SRPB. Los análisis exploratorios se llevaron a cabo mediante el uso de distribuciones de frecuencia univariadas y medidas descriptivas; validación de consistencia interna y cálculos de las dimensiones de las puntuaciones de la escala. Los resultados mostraron que las dimensiones relacionadas con la espiritualidad, la religión y las creencias personales adoptadas por los pacientes como estrategias para la mejora de su calidad de vida en esta investigación se confirmaron en las puntuaciones más altas en las áreas de WHOQOL SRPB en dos fases; había diferencias sólo en la dimensión sentido de la vida y la fuerza espiritual. Se espera que este estudio pueda resaltar la importancia del cuidado espiritual y emocional.

DESCRIPTORIOS: Traumatismos de la médula espinal. Espiritualidad. Religión. Calidad de vida. Enfermería.

INTRODUCTION

Spinal cord injury (SCI) is an aggression to the spinal cord, which results in the decrease or absence of sensibility and muscle strength, as well as neuro-vegetative disorders of body segments located below the injury, and can lead to impairment of the urinary, intestinal, respiratory, circulatory, sexual and reproductive systems.¹

The sequelae and difficulties these people face to return to their family and social life interfere with their quality of life and, depending on their severity and irreversibility; they can lead to changes and biopsychosocial modifications, with bodily, psychological and social repercussions, requiring adaptation to the new life.²

Among the psychological problems, the depressive disorder is one of the most common in people with SCI and its severity varies from minor depression to adjustment disorders and major depressive episodes. The type, duration and scope of the symptoms and their effect on the functions are variable. However, subclinical depression levels have been investigated and demonstrated having major impact on health, particularly in the performance of activities related to daily living and in the relationships with people without disabilities.³

People with SCI need physical, social, psychological and spiritual support for the promotion of quality of life, since they participate in a long rehabilitation program, which in most cases does not lead to cure, but only helps to adapt to the new life.⁴

It is clear that lifestyle changes due to SCI, especially those related to locomotion and psychological aspects, may affect different domains of quality of life.

In our country, there are few studies relating quality of life (QOL) and spinal cord injury. However, assessing the quality of life is of great importance to these people. A study evaluating quality of life concluded that the physical, social, emotional and mental health domains are the ones that most sacrifice the QOL of these people.⁵ There is a growing consensus that QOL is fundamental for people with spinal cord injury, especially because the life expectancy of these individuals has increased substantially over the last 30 years.⁶

Defining quality of life is complex and subjective. Nevertheless, the World Health Organization (WHO), through its experts, conceptualized QOL as individuals' perception of their position in life in the context of culture and value systems,

in which they live and in relation to their goals, personal expectations, standards and concerns.⁷ This understanding resulted in the creation of an instrument named World Health Organization Quality of Life Instrument (WHOQOL-100), which assesses QOL and includes six main domains: physical, psychological state, independence level, social relationships, environment and spirituality/religion/personal beliefs.⁸

Some articles report that the success of the WHOQOL-100 prompted the WHO to build others and to specify some domains. These instruments include the WHOQOL-SRPB, which deals with the spirituality/religiosity/personal beliefs domain (SRPB).⁹⁻¹⁰

Therefore, the WHOQOL-SRPB is an instrument developed to evaluate how spirituality, religion and personal beliefs are related to QOL in health and healthcare. The principle underlying the development of the WHOQOL-SRPB states that, starting from the perspective of QOL assessment, having a profound religious belief or not could give a transcendent meaning to life and activities of daily life and work as a strategy to deal with human suffering and existential dilemmas.¹¹

There is the need for further studies on the WHOQOL-SRPB in specific populations, of different religions and other cultural groups,¹² because, although it has been validated and proven to be reliable and valid, the instrument still requires expansion of its degree of validity.

The application of this instrument becomes relevant to public health, considering the uniqueness of its application in people with SCI, and because it can bring valuable contributions to care, especially in nursing, in relation to emotional and spiritual aspects.

Despite emphasizing the importance of the spiritual dimension in health/illness processes, as recognized by national and international nursing associations and demonstrated by scientific evidence, this dimension remains forgotten in nursing care.¹³

The nurses, as professionals present in the service, identify the particularities involved in the concepts of spirituality and religiosity, in the same way as they recognize the link between them. The applicability of these concepts in clinical nursing practice receives direct influence from their own spirituality and religiosity, as well as their professional training and fear of the repercussions of the approach of these issues directly on patients. Thus, scenarios that show patients' fragility seem

to favor the involvement of nurses with spirituality and religiosity of those under their care. In such cases, the nurse feels strengthened to provide comprehensive care that contemplates the human being in all its dimensions.¹⁴

Therefore, knowing the quality of life of people with SCI allows nurses to propose health promotion, by considering that such strategies, among other objectives, promote a psychological empowerment, strengthen self-esteem and ability to adapt to the environment, develop self-care mechanisms, solidarity and changes in lifestyle, aspects nurses envision in the care process along with quality of life.

This study aimed to evaluate the influence of spirituality, religiosity and personal beliefs in quality of life of people with SCI during hospitalization and at their homes.

METHOD

This is an exploratory and longitudinal cross-sectional study with a quantitative approach, carried out in Fortaleza-CE. The study targeted people with SCI, of both sexes, hospitalized in the neurological unit of the institution, during the data collection period, and at their homes after discharge.

The size of the study sample was calculated based on the formula suited for studies with finite populations. To calculate the sample size, the following parameters were adopted: study confidence level of 95% ($Z_{\alpha} = 1.96$); sampling error of 5.3%; a total population of 186 patients (number of hospitalizations for SCI in 2011) was used in the denominator. As the prevalence of SCI in the hospital was unknown, a 50% prevalence of patients with spinal cord injury diagnosis was adopted. Based on the above criteria, the sample was estimated as $52.9 \approx 55$ SCI patients, selected by convenience, consecutively, according to hospitalization due to a spinal cord injury diagnosis.

The following inclusion criteria were adopted: traumatic spinal cord injury diagnosis during hospitalization and SCI diagnosis for over 10 days; be able to respond to the instrument, alone or with the help of the researcher, in cases of quadriplegia; physical disability to write and visual impairment. The following exclusion criteria were adopted: presence of other associated pathology, which affects their level of awareness and guidance, such as traumatic brain injury and cerebrovascular accident. The following study discontinuation

criteria were used: patients who passed away; researchers unable to contact patients because the patients' phones were switched off or outside the area of coverage.

Data collection occurred in two phases. The first, in the hospital environment, during the hospitalization period in the ward; after selection and during the collection time, 55 patients could be interviewed. The second occurred when the patient was at home, when it was decided to apply the WHOQOL-SRPB instrument over the phone. Data could be collected from 49 patients in this phase.

The first phase of the study occurred from March to October 2013. The telephone calls always occurred one month after the first phase; and it is worth emphasizing that, for some patients, the interviewers had to call at a later moment, as their hospitalization time exceeded 30 days.

The researcher and two interviewers (Fellows) composed the team responsible for data collection and received guidelines about the study, among which the following may be noted: objectives, method and guidance on the instrument and its application. It is emphasized that interviewers started collecting data after observation and application of the instrument by the researcher responsible for this study during the pilot test.

Data were entered in the Microsoft Access version 2003 and then exported to the statistical software STATA version 8 to generate results. Exploratory analyses were performed using univariate frequency distributions, descriptive measures and graphic box plot (mean and standard deviation, median, minimum and maximum and quartiles) of the demographic, socioeconomic and clinical characteristics of the study population; validation of the internal consistency of the responses and calculation of the scores of the respective dimensions of the WHOQOL-SRPB scale in both phases of the study (in the hospital and at home).

The scores of the respective dimensions were calculated based on the sum of the four issues in each facet (total 8), and then divided by 4, ranging from 1 to 5. The average of the facets is the score of the respective dimension for each individual. The overall score was obtained, which is the synthesis of all dimensions based on the sum of "n" dimensions, divided by 8 and multiplied by 4, ranging from 4 to 20.

To compare the mean values of the groups (hospitalized or at home), Wilcoxon's average equality test was used, a nonparametric test to

compare paired samples, whose main objective was to compare the dimensions of people while they were hospitalized and at home, with the purpose of verifying significant differences between the dimensions in the two phases.

Cronbach's alpha coefficient was used to assess the internal consistency of responses to the items of the WHOQOL-SRPB scale and the following classification was adopted to assess the values reached: between 0.70 and 0.90, good internal consistency; below 0.70, weak internal consistency; and above 0.90, high concordance.¹⁵

The ethical aspects were observed in all stages of the research, in compliance with the requirements established in National Health Council Resolution number 466/12, in particular those regarding the preservation of the fundamental bio-ethical principles of respect for the individual and beneficence.¹⁶ The project received approval from the Institutional Review Board of the *Universidade Federal do Ceará*, under protocol 338.980, and from the Institutional Review Board of Instituto Dr. José Frota, under protocol 348.114.

RESULTS

This research studies spiritual, religious or personal beliefs by applying the WHOQOL-SRPB scale, throughout the phases of hospitalization and at home.

In the first stage, 55 patients with SCI participated in the study with predominance of males (87.3%). In terms of age, 25.5% were aged up to 25 years, 16.4% between 26 and 35 years, 21.8% between 46 and 55 years and 9.1% between 56 and 65; the average age was 38.1 years (SD=±13.9 years), minimum age of 15 years and maximum of 65 years. As for the distribution of self-reported skin color, mulatto color prevailed with 49.1%; black color 25.5%; white color 14.6% and yellow color 10.6%. The Catholic religion was predominant (54.6%), Protestants 23.6% and 21.8% did not participate in any religion. Regarding marital status, 36.4% were single; 32.7% married; 25.4% reported being in a stable relationship and 5.5% separated/divorced. As regards the origin of the participants, 51.9% came from the interior of the state of Ceará, and 49.1% were from the capital Fortaleza.

With regard to spiritual, religious or personal beliefs, through the application of the WHOQOL-SRPB scale and due to the discontinuation criteria, it was possible to apply the WHOQOL-SRPB in 49

people diagnosed with acute spinal cord injury (SCI) in both phases of the study.

The 32 items of the WHOQOL-SRPB scale were summarized in eight dimensions, with scores ranging from 1 to 5. In Figure 1 (box plot) and Table 1, the summary of the scores during hospitalization and at home revealed that the distributions in all dimensions proved to be asymmetrical, expressing variability in relation to the mean value and variations from 3.5 to 4.3.

In the hospitalization phase, a median value of 3.8 was observed, relative to the values of the connection with being or spiritual strength dimension. In the home-based phase, it decreased to 3.5, with a significant reduction in the interquartile difference of the home-based phase (difference between the quartiles Q75-Q25). The Sense of life dimension maintained the median 4 in the hospitalization and home-based stages, although a significant interquartile range was observed in the home-based phase, which was statistically significant ($p=0.052$) (Table 1).

The Admiration dimension showed significant variability in the pattern of answers in the hospital environment, maintaining the median value of 4 in both phases; and decreased in the variation between quartiles in the home-based environment. The Totality and integration dimension showed variations in the median values between the phases: in the hospital environment, the median value was 3.8 and, at home, it was 4.0; there was an increase in the frequency of values below the median for the home-based environment. The Spiritual force dimension maintained the median value of four with the change of environment, however, this dimension showed a significant variation in values below the median at home and presented statistically significant differences ($p=0.049$) (Table 1).

The Inner Peace dimension showed variations in the hospital environment; the median value was 3.8 and, at home, it was 4.0; there was a reduction in the variation between the quartiles and higher concentration of values below the median for the home. The Hope and optimism dimension maintained the median value of 4; the frequency values above the median increased after the change of environments. In the Faith dimension, there was an increase in the median value when changing from the hospital environment to home, from 4 to 4.2 respectively, but an increase in the frequency of values below the median for the home environment.

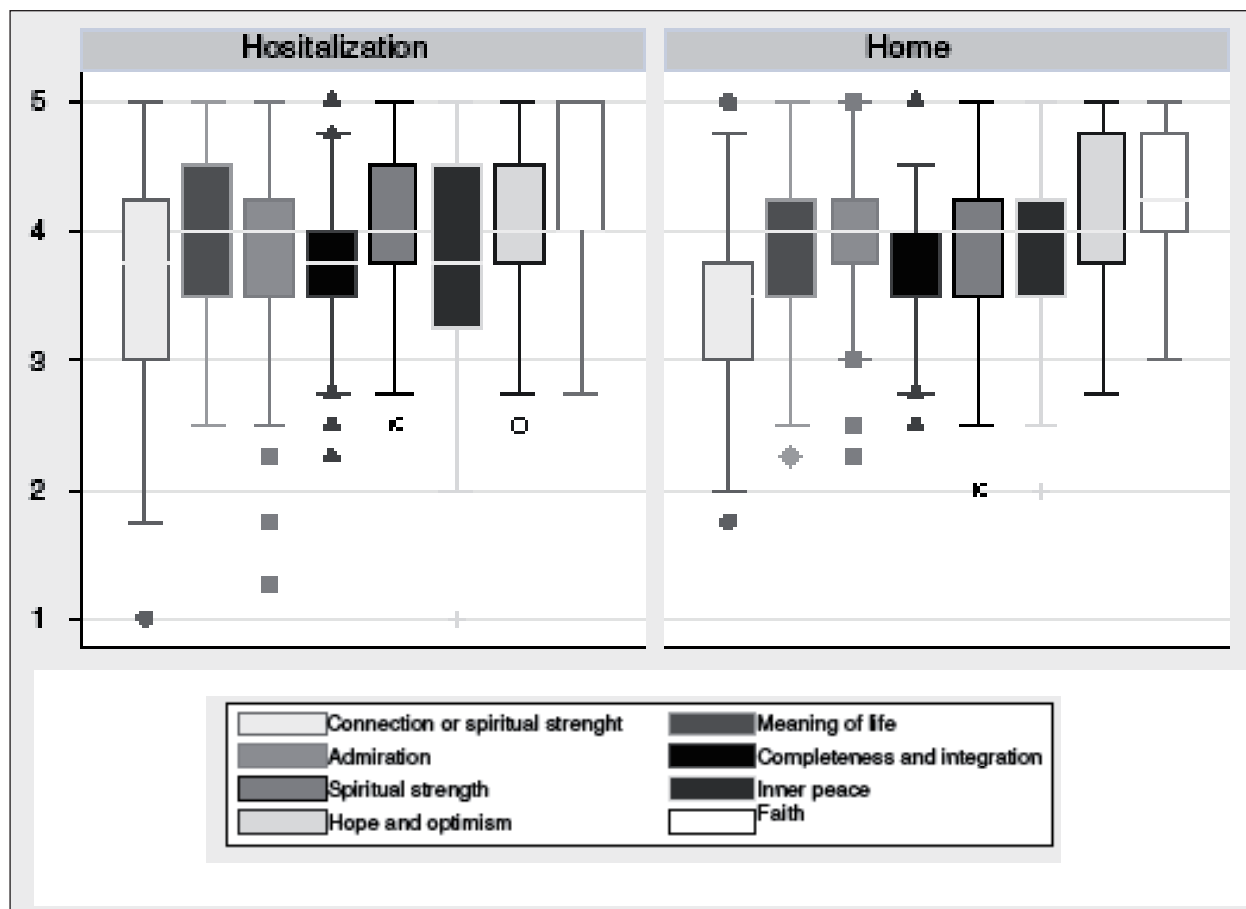


Figure 1 - Descriptive scores of the dimensions of the WHOQOL-SRPB scale of people with SCI diagnosis (n=49) in both study phases

Table 1 shows the descriptive measures for each dimension in both study phases; mean values were compared using Wilcoxon’s average equality test for paired data. It was found that only the Meaning of life and Spiritual strength dimensions were statistically different when measured in the hospital environment and in the home-based environment ($p = 0.05$); the other dimensions remained unchanged in the home-based environment.

It was observed that the average scores for each dimension, on a scale from 1 to 5, ranged from 3.4 (minimum) to 4.3 (maximum); presenting small average differences between the hospital and home-based stages. The Inner Peace dimension did not change in terms of average values with the change of environment. The overall score remained 15 (range from 4 to 20), showing that the synthesis of all the dimensions did not change between the two study stages.

Table 1 - Descriptive scores of the dimensions of the items of the WHOQOL-SRPB scale of people diagnosed with SCI (n=49) in both study phases. Fortaleza-CE, Brazil, 2013

Dimensions of the WHOQOL-SRPB scale	Median	Average (\pm SD)*	95%CI of the average†	p-value‡
Connection with spiritual being or spiritual strength				
Hospitalization	3.8	3.5 (\pm 0.9)	(3.3-3.8)	0.374
Home	3.5	3.4 (\pm 0.7)	(3.2-3.6)	
Meaning of life				
Hospitalization	4.0	3.9 (\pm 0.7)	(3.7-4.1)	0.052
Home	4.0	3.8 (\pm 0.6)	(3.6-3.9)	

(continue)

(conclusion)

Dimensions of the WHOQOL-SRPB scale	Median	Average (\pm SD)*	95%CI of the average†	p-value‡
Admiration				
Hospitalization	4.0	3.8 (\pm 0.8)	(3.5-4.0)	0.198
Home	4.0	3.9 (\pm 0.6)	(3.8-4.1)	
Completeness and integration				
Hospitalization	3.8	3.7 (\pm 0.6)	(3.5-3.9)	0.107
Home	4.0	3.8 (\pm 0.6)	(3.7-4.0)	
Spiritual strength				
Hospitalization	4.0	4.0 (\pm 0.7)	(3.8-4.2)	0.049
Home	4.0	3.8 (\pm 0.7)	(3.6-4.0)	
Inner peace				
Hospitalization	3.8	3.8 (\pm 0.8)	(3.5-4.0)	0.599
Home	4.0	3.8 (\pm 0.6)	(3.4-3.5)	
Hope and optimism				
Hospitalization	4.0	4.0 (\pm 0.6)	(3.8-4.2)	0.090
Home	4.0	4.2 (\pm 0.6)	(4.0-4.3)	
Faith				
Hospitalization	4.0	4.2 (\pm 0.6)	(4.1-4.4)	0.575
Home	4.2	4.3 (\pm 0.6)	(4.1-4.4)	
Domain Scoring§				
Hospitalization	15.8	15.5 (\pm 2.3)	(14.8-16.2)	0.992
Home	15.5	15.5 (\pm 1.7)	(15.0-16.0)	

*SD=Standard Deviation; †IC=Reliability index; ‡Wilcoxon's average equality test for paired data; §Sum of all dimensions of the scale with variation from 4 to 20.

Table 2 shows the results of the internal consistency evaluation of the responses to the items of the WHOQOL-SRPB scale, which were achieved by applying the global and partial Cronbach's alpha coefficient for each dimension, in both study phases.

The global alpha coefficient was 0.95 in the first study phase and 0.92 in the second phase,

showing high internal consistency among the responses to the scale items. By analyzing the partial alpha for each dimension (with the removal of the items from each respective dimension), the internal consistency of the responses remained high, similarly to the global pattern, ranging from 0.91 to 0.95.

Table 2 - Evaluation of the internal consistency of the responses of the items according to dimensions of the WHOQOL-SRPB scale of people diagnosed with SCI (n=49), in both study phases. Fortaleza-CE, Brazil, 2013

Dimensions of the WHOQOL - SRPB scale	Cronbach's Alpha Coefficient*	
	Hospitalization	Home
Connection with spiritual being or spiritual strength	0.94	0.92
Meaning of life	0.94	0.92
Admiration	0.95	0.92
Completeness and integration	0.95	0.91
Spiritual strength	0.94	0.91
Inner peace	0.94	0.91
Hope and optimism	0.95	0.91
Faith	0.94	0.91
Global Cronbach's alpha	0.95	0.92

*Cronbach's alpha with the removal of the items from the dimension

DISCUSSION

Although it is difficult to measure and evaluate the aspects related to spirituality, religiosity

and beliefs in terms of influence in health improvements, the scientific community recognizes them as such and always refers to the need for further research in this area.

The WHOQOL-SRPB instrument permitted knowing the influence of these aspects on the QOL of people with spinal cord injury during their hospitalization and after discharge, at their homes. It is also known that the theme is widely discussed in holistic care, although its application still does not occur with significant frequency. In the case of SCI, there is a clear need for support associated with psychological, emotional and spiritual aspects.

In a study on QOL of people with spinal cord injury, in which a WHO instrument was applied, the WHOQOL-Bref, the environmental and physical domains achieved the worst evaluation scores and the psychological and social relations domains achieved the highest scores in the evaluation. The evaluation of the psychological domain showed that respondents rely on personal beliefs, spirituality and religion, accept their physical appearance and maintain their self-esteem and ability to think, learn and focus.⁴

Regarding the identification of aspects related to spirituality, religiosity and personal beliefs patients adopted as strategies to improve their quality of life, this study confirms the high scores in the domains of the WHOQOL-SRPB in both phases, and the domains that stood out were related to Hope and optimism, Spiritual strength and Faith.

In the collection with regard to feelings, it was observed qualitatively that patients with SCI use much feelings of optimism, hope and faith to face life difficulties and these domains corresponded to those they found easier to respond, some even explained and developed, justifying and reporting the overcoming of facts in their lives.

As for the descriptive measures of each dimension, in both phases of the study, the mean values were checked and showed that only the Meaning of life and spiritual strength dimensions were statistically different when measured in the hospital environment and at home (value $p \leq 0.05$); other dimensions remained unchanged at home.

One study reported that the ability to keep on living after injury varies for each person. Social isolation was a common point among all people who participated in this study, at least at the beginning of their new life. Some with advanced age and long time of injury were getting adapted to the new life and reinserting themselves into social life. Others, for various reasons, chose not to leave the house, intensifying the isolation imposed by the excluding society we live in.¹⁷

In the qualitative study on how to find a Meaning of life after SCI, despite the difficulties arising from the transformations, it was observed that not only in relation to the physical aspect, but also to many aspects of human life, such as psychological, emotional and spiritual, the study showed that self-control and self-confidence permit overcoming difficulties, believing that the change is an opportunity for personal growth and not a threat to life, and thereby accepting a certain unpredictability of life.¹⁸

It is highlighted that the change of environment and adaptation to spinal cord injury can modify the thinking about the meaning of life because, when returning to their homes, the patients with SCI are in a familiar environment, although they have to adapt to the resulting trauma consequences.

In the Spiritual Force dimension, the presence of inner spiritual strength was evaluated and to what extent this power helps to improve the lives of individuals at difficult times. This dimension maintained the median of four with the change of environment, but showed a significant variation in the values below the median at home and statistically significant differences ($p=0.049$).

In a review,¹³ whether one is bound to assume a conventional religion or not, spirituality is an intrinsic dimension of the human being and can be experienced in many aspects, not only in religion. It is considered a living force within each of us, which leads to a greater completeness of life. It is the only and personal answer to the appeals of authenticity and to the surpassing of banality. Spirituality is the condition of every human person who seeks authenticity when dealing with him/herself, with the others and with life. It is the profound meaning of the events of their personal lives, the lives of the others and the life of the history. This search for authenticity is the inner strength that permits unifying and giving an ultimate meaning to existence.

Although this study was developed in two phases, the data collection time was short and most respondents were still in the acute phase of SCI, which may explain the findings in that these patients with spinal cord injury obtained high scores in QOL on the domains of the WHOQOL-SRPB, primarily in the areas related to Hope and optimism, Spiritual Strength and Faith. In the stage of denial, which is the time when the patients begin to perceive reality, however, they distort it and

maintain the belief in full recovery. At this point, it is expected that the team understands the patients, respecting them and providing information that awakened them to the rehabilitation process.¹⁹

Therefore, these results confirmed that aspects of spirituality, religiosity and beliefs have high scores during the disease process and help people to face this, which is also confirmed in the research,²⁰ whose results reinforce that the presence of a disease can be associated with worsening in most domains of QOL, except in the SRPB domain. Regarding QOL, the presence of chronic disease can be associated with worsening in most domains, except in the SRPB domain.²¹

FINAL CONSIDERATIONS

This research showed how aspects of spirituality, religion and personal beliefs influence the quality of life of people with spinal cord injury, due to the high scores when applying the WHOQOL-SRPB.

Being present 24 hours during care, nursing can provide quality care, not only regarding physical care, but also in relation to psychosocial and spiritual aspects and, therefore, has the opportunity to know, identify and assess the needs of patients in various aspects.

Therefore, institutions should be able to invest in their professionals and in groups of spiritual and religious support, permitting care delivery focused on spirituality and thereby helping patients to overcome such an unexpected trauma, in order to promote emotional support, reduce or even prevent mood disorders, such as depression.

It is expected that this study might awake health professionals, especially nurses, to the importance of spiritual and emotional care for people who are hospitalized for SCI. It is also considered of extreme importance to avoid imposing their religious practices to the user, at risk of harming the professional-patient relationship and the respect that should be mutually maintained.

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