

## ORIGINAL ARTICLE

### RELIGIOUS/SPIRITUAL COPING: A STUDY WITH FAMILY CAREGIVERS OF CHILDREN AND ADOLESCENTS UNDERGOING CHEMOTHERAPY\*

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#### ABSTRACT

**Objective:** To identify the style of religious-spiritual coping used by family caregivers of children and adolescents undergoing chemotherapy.

**Method:** Quantitative descriptive study. Data from 63 family caregivers in a pediatric hospital in Distrito Federal was collected through a questionnaire for characterization of the sample and the religious/spiritual coping scale. Statistical Package for the Social Sciences version 16.0 and Microsoft Excel 2013 were used in the analysis.

**Results:** The total value of religious/spiritual coping obtained was 3.7. The mean value of positive religious/spiritual coping was 3.4 and of negative religious/spiritual coping was 2. The negative religious/spiritual coping (NRSC)/positive religious/spiritual coping (PRSC) ratio was 0.6, with a tendency for the use of negative strategies in religious/spiritual coping.

**Conclusion:** Family caregivers used religious-spiritual coping through positive and negative strategies, with a predominance of negative strategies. These results support nursing care by associating the competencies for care delivery in the physical dimension to the spiritual needs of the family unit.

**DESCRIPTORS:** Psychological adaptation; Religion; Spirituality; Caregiver; Nursing care.

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## **COPING RELIGIOSO/ESPIRITUAL: UM ESTUDO COM FAMILIARES DE CRIANÇAS E ADOLESCENTES EM TRATAMENTO QUIMIOTERÁPICO**

### **RESUMO**

**Objetivo:** identificar o estilo de coping religioso-espiritual utilizado entre familiares de crianças e adolescentes em tratamento quimioterápico.

**Método:** estudo descritivo quantitativo. Os dados foram coletados com 63 familiares cuidadores em um hospital pediátrico no Distrito Federal, com um questionário para caracterização da amostra e a escala coping religioso/espiritual. Na análise utilizou-se os programas Statistical Package for the Social Sciences versão 16.0 e Microsoft Excel 2013.

**Resultados:** o valor do coping religioso/espiritual total obtido foi de 3,7. A média de coping religioso/espiritual positivo foi de 3,4 e negativo foi de 2. A razão coping religioso/espiritual negativo/coping religioso/espiritual positivo foi de 0,6 com direcionamento do uso do coping religioso/espiritual para as estratégias negativas.

**Conclusão:** os familiares cuidadores utilizaram o coping religioso-espiritual empregando tanto estratégias positivas quanto negativas, com predomínio das estratégias negativas. Esses resultados fundamentam a assistência de enfermagem associando as competências para o cuidado da dimensão física às necessidades espirituais de toda a unidade familiar.

**DESCRIPTORIOS:** Adaptação psicológica; Religião; Espiritualidade; Cuidador; Cuidados de enfermagem.

## **LA UTILIZACIÓN DE ENFRENTAMIENTO RELIGIOSO Y ESPIRITUAL: UN ESTUDIO CON FAMILIARES DE NIÑOS Y ADOLESCENTES EN QUIMIOTERAPIA**

### **RESUMEN**

**Objetivo:** identificar el estilo de enfrentamiento (coping) religioso-espiritual que se utiliza entre familiares de niños y adolescentes en quimioterapia.

**Método:** estudio descriptivo cuantitativo. Se obtuvieron los datos con 63 familiares cuidadores en un hospital pediátrico en Distrito Federal, por medio de cuestionario para caracterización de la muestra y la escala coping religioso/espiritual. En el análisis se utilizaron los programas Statistical Package for the Social Sciences versión 16.0 y Microsoft Excel 2013.

**Resultados:** el valor del coping religioso/espiritual total obtenido fue de 3,7. El promedio de coping religioso/espiritual positivo fue de 3,4 y negativo fue de 2. La razón coping religioso/espiritual negativo/coping religioso/espiritual positivo fue de 0,6 con superioridad de uso de coping religioso/espiritual para las estrategias negativas.

**Conclusión:** los familiares cuidadores utilizaron el coping religioso-espiritual aplicando tanto estrategias positivas como negativas, con predominio de las estrategias negativas. Esos resultados fundamentan la asistencia de enfermería asociando las competencias para el cuidado de la dimensión física a las necesidades espirituales de toda unidad familiar.

**DESCRIPTORIOS:** Adaptación psicológica; Religión; Espiritualidad; Cuidador; Cuidados de enfermería.

## INTRODUCTION

Coping comprises a set of self-regulation resources used by individuals to handle stressful situations resulting from internal or external demands, through cognitive and behavioral actions and strategies. It can be didactically classified into two basic types: problem-focused coping and emotion-focused coping. In the first type, the individuals try to change or eliminate the source of stress by researching the problem and learning management skills to solve it. In the second type the individual modifies the emotions that accompany stress perception by releasing, distracting or managing their mental state<sup>(1-2)</sup>. Despite their different concepts, these dimensions are not functionally exclusive, i.e., the individuals' responses to stressful situations may include both problem solving and emotional regulation aspects<sup>(3)</sup>.

Religious/spiritual coping (RSC) occurs when religious and spiritual beliefs are used to deal with stressful situations. RSC is defined as the use of religion, spirituality or faith to manage the suffering triggered by the stressor element<sup>(4)</sup>. RSC is aimed to reconcile religious and spiritual beliefs in their multiple dimensions, in order to seek significance, control, spiritual comfort, closeness with God and life transformation<sup>(5)</sup>.

However, RSC does not always provide relief and comfort, since the use of religious and spiritual beliefs may result in beneficial or positive responses called positive religious-spiritual coping (PRSC), but also in negative responses, a negative religious-spiritual coping (NRSC)<sup>(6)</sup>.

Since RSC may favor both the adoption of healthy and harmful behaviors in the management of stressful situations, this phenomenon must be well understood to avoid overvaluation of its results.

Therefore, it is important to clarify that studies on this theme indicate that PRSC strategies are much more used in the management of stressful situations than NRSC strategies. There are high rates of use of these strategies by individuals who believe spiritual/religious support is necessary and want to receive such care from nurses during their treatment<sup>(7)</sup>. In contrast, NRSC is related to negative responses, such as decline in life satisfaction and lower quality of life<sup>(7)</sup>.

Thus, religious and spiritual beliefs may be satisfactory coping strategies, representing an important aspect to be considered in the health care area<sup>(8)</sup>. Therefore, identification of the use of PRSC or NRSC is important for the planning of nursing care, in order to favor the use of healthy coping strategies to deal with the complexity of the process of illness and treatment.

In this regard, RSC can be considered an important support to the families of children and youngsters receiving chemotherapy. It is known that the diagnosis of cancer interferes in the balance of the family system, generating uncertainty about the possibility of cure or the lethality of the disease. The negative symbolism associated to the idea of loss of a young member in the family is perceived as an interruption of the biological cycle of this individual, leading to feelings of helplessness, frustration, sadness and distress<sup>(9)</sup>.

During chemotherapy treatment, feelings associated with the finitude of life are exacerbated by the effects of the treatment. The intense suffering of young sick persons raises the stress levels of the relatives, overburdening family caregivers who, besides dealing with individuals that cannot make their own decisions independently because of their young age, will also have to deal with the demands related to the acute condition<sup>(10)</sup>.

In this context, a study in the field of Pediatric Oncology reports that family members/caregivers usually use religious and spiritual beliefs as coping strategies and support mechanisms for the obstacles faced in chemotherapy routine. The attachment of caregivers to faith is as a source of support and provides confidence in the possibility of miracle and healing<sup>(11)</sup>.

Quality of life has been the subject of different studies that investigated its relationship with positive RSC. A study that aimed to evaluate, among other aspects, the relative contribution of religiosity and styles of religious coping in 353 people who experienced events related to the war in Bosnia and Herzegovina found that religious/spiritual coping played a crucial role in the positive estimation of quality of life<sup>(12)</sup>.

Thus, given that: 1 - spiritual needs are inseparable from other fundamental needs of the individuals and integrate cognitive, experiential and behavioral aspects; 2- RSC can be used in a beneficial or harmful way in the management of stressful situations; 3- RSC can influence the quality of life of the family unit; 4 - the need for nursing care planning aimed at integrality and multidimensionality regarding family beliefs and values in the process of childhood and adolescent cancer, the following question is posed: Does the RSC style used by family caregivers of children and adolescents undergoing chemotherapy tend to benefit or undermine the healthy balance of the family unit?

In view of the aforementioned, the present study aimed to identify the type of religious-spiritual coping used by family members of children and adolescents receiving intravenous chemotherapy.

## METHOD

A quantitative and descriptive study conducted at a pediatric hospital in Distrito Federal, Brazil. The sample consisted of family caregivers of children and adolescents receiving intravenous chemotherapy.

Individuals aged 18 or over who provided direct care to young patients, regardless of the degree of kinship, were included in the study. Family members who cared for children and adolescents in isolation were excluded.

Data was collected from March to July 2017 through the use of a questionnaire for the characterization of the sample, including clinical information about the patients and the application of the religious/spiritual coping Scale, adapted and validated in Brazil with an excellent internal consistency index (0.97) from the North American Religious Cope scale (RCOPE)<sup>(6,13)</sup>.

The variables considered in the study were age, gender, marital status, kinship, schooling and religion, clinical conditions of the child and adolescent (time elapsed since diagnosis and length of time undergoing chemotherapy treatment), as well as RSC strategies used by the family, obtained through the application of the RSC scale.

The RSC scale is an instrument composed of 87 questions divided into two subscales: positive spiritual religious coping with 66 issues and negative spiritual religious coping with 21 questions. The questions are objective and use Likert scale responses, in which the value ranges from 1 (a little) to 5 (a lot). In order to achieve the goal of this study, the original expression of the scale, i.e. "At that moment, think about the most stressful situation you have experienced in the last three years"<sup>(13)</sup>, has been replaced by: "Think about the stressful condition experienced during your child's or adolescent chemotherapy and answer the questions reflecting on this situation."

Analysis of the scale is performed by calculating the rates used to evaluate the answers provided by the respondents. PRSC and NRSC rates are obtained with the average number of questions of each dimension. These two rates are classified as dimensional rates, which form the basic measures of the scale and indicate the different types of RSC performed by the respondent, as well as the levels of this coping<sup>(13)</sup>.

Total RSC indicates the total quantity of RSC practiced by the individual, through the mean of the positive RSC rate and the average responses to the 21 items of the inverted

negative RSC (inverted NRSC). The NRSC/PRSC ratio shows the percentage of negative RSC used in relation to the positive NSC, through simple division between the basic rates. These are general rates and integrate all the information obtained from the scale, which relates positive and negative religious/spiritual coping in order to obtain general rates, using all items of the religious/spiritual coping scale. In short, a profile of the sets of behaviors of the respondents is presented and is used to show the interaction between the basic measures<sup>(13)</sup>.

If the same individual uses positive and negative RSC to deal with stress, the ratio between these amounts (NRSC/PRSC) allows us to determine if the consequences of total religious/ spiritual coping use are positive or negative for the respondents. The study that validated the scale in Brazil affirmed that the minimum proportion required to obtain a positive balance in the quality of life of the individual, regarding the use of RSC, was 2 PRSC: 1 NRSC, generating a NRSC/PRSC ratio less than or equal to 0.50<sup>(13)</sup>.

The parameters used to analyze the mean values of the total RSC, PRSC and NRSC rates were none or derisory (1.00 to 1.50); low (1.51 to 2.50); mean (2.51 to 3.50); high (3.51 to 4.50) and very high (4.51 to 5.00)<sup>(13)</sup>.

After collection, data were analyzed by the Statistical Package for Social Sciences (SPSS) version 16.0 and Microsoft Excel 2013. Chi-square test was used to verify the association between the assessed profile variables and religious/spiritual coping, with a significance level of 0.05 (alpha = 5%).

This study complied with national and international standards on ethical standards of scientific research involving human subjects and was approved by the Ethics and Research Committee of the University of Brasília under protocol no 1,963,386.

## RESULTS

Of the 63 family caregivers who composed the sample, 55 (87.30%) were female; 48 family caregivers (76.19%) were mothers; 22 (34.9%) were aged 21-30 years; 26 (41.27%) were married; 30 (47.62%) had completed secondary education and 36 (57.14%) declared themselves as evangelicals. The ages of the children ranged from 6 months to 15 years, 12 children/ adolescents (19.05%) had been diagnosed 1 to 3 months ago, 18 (28.57%), 18 (28.57%) have been receiving chemotherapy for 1 to 3 months, and 32 (50.79%) were diagnosed with acute lymphoid leukemia. Table 1 shows the values of the analysis of the dimensional and general rates of the RSC scale.

Table 1 – RSC of relatives/caregivers of children and adolescents undergoing chemotherapy. Brasília, DF, Brazil, 2017

Coping Religious/ Spiritual	Mean	Standard deviation	Median*	Min**	Max***
Total RSC	3.7	0.3	3.8	2.9	4.5
Positive RSC	3.4	0.6	3.5	2.3	4.5
Negative RSC	2.0	0.5	1.9	1.2	3.2
RATIO	0.6	0.2	0.6	0.3	1.1

\*Mdn= median value; \*\*Min= minimum value, \*\*\*Max= maximum value



RSC as a coping strategy used by family caregivers is analyzed considering the total RSC rate, whose value is 3.7 (Table 1), indicating a high use compared to other coping strategies. Thus, RSC is an important family strategy in the coping with chemotherapy in children and adolescents.

The use of positive RSC strategies was analyzed based on the average questions related to PRSC. The result of 3.4 (Table 1) indicates that its use on negative strategies is of medium intensity. Some positive factors had higher means such as P4, with a mean of 4.0 and P1 with a mean of 3.9 (Table 2). These results indicate high use of these strategies by family caregivers who have a positive attitude towards their own transformation and/or the transformation of their lives and expect God's intervention to cure their children/adolescents receiving chemotherapy. Analysis of secondary factor rates (P1-P8 / N1-N4) provided a detailed view of the set of RSC strategies most commonly used by family caregivers (Tables 2 and 3).

Table 2 - Positive factors of family caregivers of children and adolescents undergoing chemotherapy. Brasília, DF, Brazil, 2017

Positive factors	Mean	Standard deviation	Mdn*	Min**	Max***
P1 Factor (Transformation of oneself and/or one's life)	3.9	0.6	3.9	2.8	4.9
P2 Factor (Help seeking actions)	2.9	0.8	3.1	1.6	3.9
P3 Factor (Offering assistance to other people)	3.3	0.6	3.3	2.5	4.3
P4 Factor (Positive attitude towards God)	4.0	1.4	4.7	1.2	4.9
P5 Factor (Personal search for spiritual growth)	3.7	1.0	4.0	1.9	4.4
P6 Factor (Seeks others in the institutional environment (dimension) )	3.1	0.6	3.2	1.9	4.0
P7 Factor (Personal search for spiritual knowledge)	2.8	1.0	2.9	1.3	3.7
P8 Factor (Withdrawal through God, religion and/or spirituality)	3.5	0.9	3.8	2.5	4.3

\*Mdn= median value; \*\*Min= minimum value, \*\*\*Max= maximum value

Table 3 – Negative factor of family caregivers of children and adolescents undergoing chemotherapy. Brasília, DF Brazil, 2017 (continues)

Negative Factor	Mean	Standard deviation	Mdn*	Min**	Max***
N1 Factor (Negative reevaluation of God)	1.5	0,3	1.4	1.2	2.2
N2 Factor (Negative attitude towards God)	2.5	1,4	2.0	1.5	4.5

N3 Factor (Negative reevaluation of significance)	2.5	0.4	2.3	2.2	3.1
N4 Factor (Dissatisfaction with the others in the institutional environment)	1.4	0.1	1.5	1.2	1.5

\*Mdn= median value; \*\*Min= minimum value, \*\*\*Max= maximum value

Regarding negative RSC strategies, analysis of the mean 2.0 (Table 1) indicates low use of these strategies. Analysis of the negative factors that compose this strategy (Table 3) showed that factors N2 and N3 obtained means of 2.0 and 2.5, respectively, indicating a low use. However, factor N2 includes the question "I prayed for a miracle" that obtained a mean of 4.5, indicating very high use. This analysis shows the patient's family members' expectations that resolution will happen through divine interference and that things will go back to the way they were before the illness.

RSC can also be analyzed by the NRSC/PRSC ratio that provides information about the percentages of use of positive and negative strategies. In the present study, the NRSC/PRSC ratio obtained a value of 0.6 (Table 1) indicating a tendency for the use of negative strategies in RSC during chemotherapy. This tendency for the use of negative coping strategies can be related to the fact that families sometimes expect that God will intervene and grant a miracle that will cure their sick children and adolescents.

Chi-square test can be used to test the hypothesis of a relationship between two categorical variables (rows and columns) of a cross tabulated contingency table. If the p-value is greater than 0.05, the null hypothesis is not rejected. Table 4 shows the respective p-value and the variables whose association was tested. There was no statistically significant relationship between the variables tested and the RSC rates of the respondents.

Table 4 - Chi-square test: tested variables and p-value. Brasilia, DF, Brazil, 2017

Variable	p-value
Age	0.09
Marital status	0.06
Gender	0.17
Kinship	0.47
Education	0.10
Religion	0.23
Time elapsed since patient diagnosis	0.24
Length of time undergoing chemotherapy	0.55

## DISCUSSION

The results indicate that relatives used RSC as a strategy to respond to the stressful situation caused by the illness of their young family members. This finding corroborates other

studies involving relatives of critically ill patients, and highlights the greater effectiveness of this type of coping compared to other strategies used to cope with life threatening conditions<sup>(14-15)</sup>.

Research on the use of religious/spiritual coping with 101 cancer patients undergoing chemotherapy showed that the participants resorted to RSC as a strong coping strategy<sup>(7)</sup>.

In the process of mobilization of responses among family caregivers, both positive and negative strategies of RSC were used, though with focus on negative strategies. As for the positive RSC strategies, they were related to an optimistic perception of God's intervention to promote the cure of the young patients. From this perspective, the family members used the experiences related to the disease to transform themselves or their lives.

This tendency has also been described in studies with individuals with different ages where the use of the positive dimension is highly related to the perception of control and independence regarding the effects of disease and treatment, indicating a better quality of life<sup>(14-15)</sup>.

It can also be said that the use of the strategy of positive attitude towards God reinforces the beneficial influence of religiosity and spirituality in the processes of coping with the challenges posed by serious illnesses<sup>(14-16)</sup>.

On the other hand, the negative dimension of RSC used by family caregivers showed a negative attitude, i.e. a negative reassessment of the meaning of the event experienced. NRSC is related to passive and delegating coping strategies in which the individuals do not take control of their lives and tend to submit themselves to a transcendent force. The individual who uses this style of coping may have a distorted perception of reality and have difficulty in facing problems<sup>(15-19)</sup>.

Deferring the responsibility of problem solving to God was reported in studies that compared the effects of RSC between healthy people and patients facing advanced cancer. Negative strategies were more used in the second group, corroborating the possible existence of a negative impact of the disease in the spirituality of those involved<sup>(15-18)</sup>.

This hypothesis can also be attributed to the fact that the individuals are experiencing events they have no control over, such as chronic diseases and the finitude process itself. People with less coping abilities tend to have a passive attitude towards disease because they believe they have no control over what is happening. Lack of control over the side effects of chemotherapy may have influenced the NRSC of family caregivers<sup>(14-17)</sup>.

Some authors suggest that people tend to resort to divine support and help in critical situations, and at same time want God to take full control and responsibility for solving their problems<sup>(14-17)</sup>.

It should be stressed that the tendency for the use of negative strategies may indicate a worse quality of life of the family unit, but particularly of family caregivers, which was demonstrated in other studies that associated strategies of religious/spiritual coping and quality of life<sup>(15,18)</sup>.

In this study, the negative experience of family caregivers during chemotherapy treatment suggests that the religious beliefs of these relatives were questioned when stressful situations were faced<sup>(14-16,18)</sup>.

The limitations of the present study are associated with its cross-sectional design that prevents the follow-up of possible changes in the use of RSC from diagnosis to the end of the treatment. Another limitation concerns the sample size, since data was collected from only one pediatric chemotherapy treatment service.



## CONCLUSION

The results of this study indicate that religious/spiritual coping was an important coping strategy used by family caregivers during chemotherapy. PRSC prevailed, despite the tendency of many relatives to resort to NRSC.

The use of PRSC enabled the transformation of the lives of family caregivers and an opportunity for getting closer to God. In turn, the results of the use of NRSC may suggest a transfer to God of the responsibility of curing the disease and restoring normality to both the patients and their families.

The tendency of using NRSC indicates the need to seek strategies to minimize the effects of the disease. It should be noted that the association between disease and divine punishment entails immediate and/or lasting effects that may pose risks to the balance of the family unit, impacting well-being, quality of life and adherence to treatment. Therefore, RSC is an important variable in the understanding of the relationship between religion/spirituality and the health of the family unit.

The recognition of the type of RSC used in nursing care is in line with the new models of health care that value integrality, humanized care and health promotion. This approach allows the planning and implementation of appropriate interventions, aiming to qualify nursing care regarding the competencies for care to the physical body and the spiritual needs of caregivers, children, adolescents and the family unit.

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**Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - RGJ, PSM**

**Drafting the work or revising it critically for important intellectual content - RGJ, PSM, MSB**

**Final approval of the version to be published - MSB**

**Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - RGJ, MSB**

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