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Influence of religiosity/spirituality on informal caregivers of children with leukemia

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Abstract

Faced with diagnosis and treatment of serious illness in children, including oncology, parents, especially mothers, tend to fully assume the demands of care and, consequently, must develop situational coping strategies. In this regard, this descriptive and cross-sectional study sought to identify the use of religious/spiritual coping by informal caregivers of children with acute lymphoid leukemia via the Brief Religious/Spiritual Coping (SRCOPE) scale. A total of 30 informal caregivers participated in the study, presenting high religious/spiritual coping (mean=3.90; SD=0.34) regarding positive methods (mean=3.67; SD=0.48). Finally, results show that mothers use religious/spiritual coping deal with the imposed demands for care, linked to the child's health condition. This reinforces the possibility of using spirituality and or religiosity as indicators of physical and mental well-being, since the quality of care is closely related to the caregivers' health.

Keywords: Caregivers. Spirituality. Religion. Adaptation, psychological. Medical oncology.

Resumo

Influência da religiosidade/espiritualidade em cuidadores informais de crianças com leucemia

Perante diagnóstico e tratamento de doença grave em crianças, incluindo a oncológica, os pais, em especial as mães, tendem a assumir integralmente as demandas de cuidados, necessitando desenvolver estratégias de enfrentamento situacional. Nesse sentido, este estudo descritivo e transversal objetivou identificar o uso do *coping* religioso/espiritual em cuidadores informais de crianças com leucemia linfoide aguda mediante aplicação da escala de *coping* religioso/espiritual breve. Participaram 30 cuidadores informais, que apresentaram *coping* religioso/espiritual alto (média=3,90; Dp=0,34) na modalidade positiva (média=3,67; Dp=0,48). Por fim, identificou-se que as mães utilizam *coping* religioso/espiritual para lidar com a demanda de cuidados a elas imposta, vinculada à condição de saúde da criança. Com isso, reforça-se a possibilidade de utilizar a espiritualidade e/ou a religiosidade como indicadores de bem-estar físico e mental, visto que a qualidade dos cuidados prestados está intimamente relacionada à saúde de quem cuida.

Palavras-chave: Cuidadores. Espiritualidade. Religião. Adaptação psicológica. Oncologia.

Resumen

Influencia de la religiosidad/espiritualidad en cuidadores informales de niños con leucemia

Ante el diagnóstico y tratamiento de una enfermedad grave en niños como el cáncer, los padres, sobre todo las madres, tienden a asumir plenamente las demandas de cuidado, por lo que necesitan desarrollar estrategias de afrontamiento de la situación. Este estudio descriptivo y transversal tuvo por objetivo identificar el uso de coping religioso/espiritual en los cuidadores informales de niños con leucemia linfocítica aguda mediante la aplicación de la escala de coping religioso/espiritual breve. Participaron 30 cuidadores informales, quienes presentaron un alto coping religioso/espiritual (media=3,90; DE=0,34) en la modalidad positiva (media=3,67; DE=0,48). Se identificó que las madres utilizan coping religioso/espiritual para hacer frente a la demanda de cuidados que realizan, relacionada al estado de salud del niño. Esto refuerza la posibilidad de utilizar la espiritualidad y/o la religiosidad como indicadores de bienestar físico y mental, ya que la calidad de la asistencia prestada está relacionada directamente con la salud del cuidador.

Palabras clave: Cuidadores. Espiritualidad. Religión. Adaptación psicológica. Oncología médica.

Research

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Acute lymphoblastic leukemia (ALL), a malignant hematological neoplasm, is one of the most common cancers in children aged two to five years, with prevalence in males. Among leukemias, it accounts for 70% to 80% of cases in Brazil [1].

Of unknown etiology, ALL has several associated risk factors, such as susceptibility to the disease, chromosomal damage secondary to exposure to physical or chemical agents, genetic, immunological, viral factors, high birth weight, previous miscarriage and maternal behavior (alcohol consumption, use of hallucinogenic drugs, exposure to radiation, exposure to insecticides and agrochemicals) [1,2].

Signs and symptoms vary, deriving from bone marrow involvement and include anemia, thrombocytopenia, neutropenia, fever, bone pain, increased testicular volume, central nervous system involvement, among others [3]. Treatment is long lasting (between two and three years), and may include chemotherapy, immunotherapy, radiotherapy, bone marrow transplantation or a combination of different methods. Moreover, early diagnosis is essential to increase survival and, generally, cure [4].

Despite advancements in medicine, cancer, as a life-threatening and costly disease, continues to cause panic among patients and their families, bringing suffering and uncertainty. In fact, a cancer diagnosis cause breakdowns and implies sudden routine changes to the child, caregivers and family members [5]. Psychic and behavioral manifestations, permeated by feelings of frustration, helplessness, insecurity and fear, also occur [6].

Parents, regardless of specific training, often assume the role of main caregivers and perform all care activities, and are thus named informal caregivers [7,8]. Psychologically unprepared to cope with the illness process, these caregivers often become destabilized due to this vulnerability. Such accumulation of roles and fraught emotional state leaves them more susceptible to developing stress and anxiety, for example [8].

The physical and mental fatigue of caregivers and family members is evident, and relates to full dedication to meeting the sick child's needs. During treatment, caregivers experience mixed feelings, such as hope for a cure and the threat of losing their child. To face such situation, they might resort to coping strategies, including religious/spiritual coping. This implies using religion and/or spirituality as a way to give caregivers comfort and strength to accept the child's chronic situation, in a delicate, challenging moment and full of stressful circumstances [5,9,10].

Religious/spiritual coping can be positive or negative. Positive coping triggers favorable effects on the practitioner, who believes in God's love, support, and warmth through religious literature, prayers and forgiveness. Conversely, negative coping harms the practitioner, who doubts God's love and existence, blaming Him for the disease, which can be seen as divine punishment [11,12].

Although most caregivers of children undergoing cancer treatment mobilize spirituality/religiosity in a positive way, considering faith as supporting pillar while waiting for a cure, some practice negative religious/spiritual coping, in which the caregiver transfers all responsibilities to God and sometimes see the disease as a divine punishment [5,10].

Since religious and spiritual beliefs can be satisfactory strategies in coping with illness, these are a key aspect to be considered in health care. Identifying the practice of religious/spiritual coping is important in planning care for both the patient and the caregiver, to favor coping with the complexity of the illness and treatment process. Thus, this study sought to identify the religious/spiritual coping practiced by informal caregivers of ALL child patients.

Method

A descriptive, quantitative, cross-sectional study was conducted in a large philanthropic hospital located in São Paulo, Brazil. A total of 30 main informal caregivers, aged 18 years or over, of children diagnosed with ALL, who were accompanying them during hospitalization participated in the research. Caregivers using psychotropic drugs, such as antidepressants, anxiolytics, antipsychotics and mood stabilizers, were excluded, as these drugs can affect perception/attention.

Sociodemographic data (age, gender, education, religion, occupation and marital status) were collected by means of a sociodemographic questionnaire. The use of spirituality/religiosity as a coping mechanism by informal caregivers was

assessed by the Brief Religious/Spiritual Coping Scale (Brief SRCOPE) [13].

Validated in Brazil and with adequate psychometric properties, the Brief SRCOPE Scale consists of 49 items grouped into 11 factors, seven of which address positive religious/spiritual coping (PRSC-34 items) and four relates to negative religious/spiritual coping (NRSC-15 items) [13,14]. Seeking to identify the stressor that triggered the need for religious/spiritual coping, the instrument presents a descriptive question, which asks for a brief report on the greatest stress experienced in the last three years, which, for this study, was related to the child's ALL diagnosis/treatment.

Answers are given on a 5-point Likert scale, resulting in the following score: from 1 to 1.5 means none or negligible; from 1.51 to 2.5, low; from 2.51 to 3.5, moderate; 3.51 to 4.5, high; and 4.51 to 5, very high [13]. Data were organized using Excel 2015 , and underwent descriptive statistical analysis.

The research was approved by the Ethics Committee for Research involving Human Beings of the hospital. All participants formalized their participation by signing the informed consent form, in line with the National Health Council Resolution No. 466/2012 [15].

Results

Of the 30 participants, 17 (56.6%) were aged between 31 and 40 years, 27 (90%) were female (all mothers), 24 (80%) lived in a stable union, 12 (40%) had complete secondary education and 19 (63.3%) were unemployed. Regarding religion, all participants declared themselves to be Christian, with equality between Catholics and Evangelicals (n=15; 50%). As for how often they participated in religious/spiritual activities, 21 (70%) reported participating once a week or more, and 29 (96.7%) considered religiosity/spirituality to be very important in their lives (Table 1).

Table 1. Distribution of participants according to religious/spiritual data (Jaú/SP, Brazil, 2021)

Variables		n	%
Religion	Catholic	15	50.0
	Evangelical	15	50.0
Importance of religion/spirituality	Important	1	3.3
	Very important	29	96.7
Attendance at church/temple/place of prayer	Once a week or more	21	70.0
	Once a month or more	7	23.3
	Once a year	2	6.7

The use of religious/spiritual coping was high among the participants (mean=3.90; SD=0.34), with prevalence of PRSC (mean=3.67; SD=0.48) compared with NRSC (mean=1.82; SD=0.68), finding corroborated by the NRSC/PRSC ratio (mean=0.49; SD=0.16) (Table 2).

Table 2. Brief Religious/Spiritual Coping Scale analysis (Jaú/SP, Brazil, 2021)

Variables	Mean	Standard deviation	Maximum value	Minimum value	Median	Q1	Q3
Total RSC	3.90	0.34	4.41	3.06	3.94	3.73	4.15
Positive RSC	3.67	0.48	4.73	2.52	3.67	3.46	3.97
Negative RSC	1.82	0.68	4.6	1.06	1.66	1.41	2.06
NRSC/PRSC Ratio	0.49	0.16	0.97	0.29	0.46	0.37	0.55

RSC: religious/spiritual coping; NRSC: negative religious/spiritual coping; PRSC: positive religious/spiritual coping; Q1: first quartile; Q3: third quartile

Among the PRSC factor, "position before God" received the highest score (mean=4.76; SD=0.42), whereas "actions in search of spiritual help" had the lowest score (mean=3.01; SD=1.05). As for NRSC, "negative position towards God" showed the highest score (mean=2.66; SD=1.07), whereas "dissatisfaction with Clergy" received the lowest score (mean=1. 45; SD=0.79) (Table 3).

Table 3. Analysis of the Brief Religious/Spiritual Coping Scale PRSC and NRSC factors (Jaú/SP, Brazil, 2021)

Variables	Mean	Standard deviation	Maximum value	Minimum value	Median	Q1	Q3
Positive RSC							
Transformation of oneself and/or one's life	3.68	0.73	5	2.11	3.77	3.33	4.11
Actions in search of spiritual help	3.01	1.05	5	1	3.2	2.6	3.6
Offer to help another	3.63	0.75	5	2.2	3.8	3.2	4
Positive position before God	4.76	0.42	5	3.4	5	4.65	5
Search for support from Clergy	3.45	0.74	5	2	3.5	3	4
Active surrender through God/religion/spirituality	4.04	0.97	5	1	4.33	3.74	4.66
Quest for spiritual knowledge	3.06	1.05	5	1	3	2.49	3.66
Negative RSC							
Negative reappraisal of God	1.47	0.80	4.2	1	1	1	1.8
Negative position before God	2.66	1.07	5	1	2.33	2	3.33
Dissatisfaction with Clergy	1.45	0.79	4.5	1	1	1	2
Negative reappraisal of meaning	2.05	0.97	5	1	2	1.08	2.66

RSC: religious/spiritual coping; NRSC: negative religious/spiritual coping; PRSC: positive religious/spiritual coping; Q1: first quartile; Q3: third quartile

Discussion

Religious/spiritual coping practices were high among informal caregivers of children with ALL, with predominance of positive coping. Diagnosis of cancer in children has short and long-term repercussions on the lives of families, who seek strategies to cope with the situation, especially religious/spiritual practices [16].

A Brazilian study conducted with eight informal caregivers of children with cancer, aged between 26 and 38 years, identified that belief in the divine is the most common way to cope with child's cancer treatment, since caregivers trust God with their hopes and recognize their limitations when facing their child's illness [16]. Religiosity and spirituality are consolation strategies for informal caregivers, as they provide tranquility and peace, easing stress [11,17]. Moreover, it is considered the best method to deal with the various difficulties in life, including cancer treatment [18].

Faith is an essential component in coping with illness, especially in children, because it promotes incessant hope for a cure before a poor prognosis or advanced stage. It is through faith that many

mothers overcome the difficult moment, remaining steadfast and hopeful [7].

Practice of religious/spiritual coping was mostly positive, especially regarding the positive position before God. Even in the face of the stress experienced, informal caregivers maintain a positive position before God, with PRSC adding benefits such as greater adherence to the child's treatment, improved perception of the caregiver's quality of life, hope, strength and faith in the divine, which minimizes negative feelings, depression, and burden [5,10].

Corroborating our findings, a Brazilian study conducted with 63 caregivers of children undergoing cancer treatment identified that PRSC was the most practiced coping method. Besides the positive position before God during the child's oncologic treatment, the caregivers became closer to God, transforming their life [10].

Such prevailing use of this strategy confirms the beneficial role played by religiosity and spirituality in the processes of coping with difficulties related to cancer diagnosis and treatment [19,20]. Besides hope in the possibility of cure, PRSC encourages the caregiver to face the situation positively, believing the affliction will end and the child's improvement is near. Prayers and cries to God sustain hope and fullness [20].

Although NRSC was practiced less, "negative position before God" showed the highest score among its items. This type of coping can lead to treatment impairment, transference of responsibility for the problem experienced to God, and association of the child's illness with divine punishment. Consequently, NRSC affects well-being, quality of life, and treatment adherence [21].

A study showed that NRSC practice results in transferring the responsibility for the situation to God, that is, the caregiver defers control to God and waits for Him to resolve it, without active participation, thus hindering cancer treatment [10]. A research conducted with 77 informal caregivers of children undergoing cancer treatment correlated NRSC strategies with symptoms of depression and worsening perceptions of quality of life [21]. According to the literature, the harms of NRSC use are diverse and include symptoms of depression, anxiety, stress and overload, which consequently interferes with the caregiver's quality of life [21,22].

A relevant information in the present study concerns the prevalence of unemployed mother caregivers, aged between 31 and 40 years. Other studies with caregivers of children and adolescents with health problems, such as cystic fibrosis, chronic diseases and dysphagia, found similar results [23-26].

Research shows that the care given to severely ill children usually falls on the mother, the main caregiver. Due to their practically exclusive dedication to the child, they withdraw from their daily activities, both due to fatigue and lack of time, and may experience depression, worse perception of quality of life, and overload [23,27].

By assuming the role of the child's main caregiver, the mother gives up on her wishes, job career, and leisure in favor of the sick child [16,28]. This situation culminates in overload, depression, and stress [29]. Associated with this, cancer treatment causes feelings of anxiety, fear, uncertainty, anguish, and physical exhaustion due to long hospitalizations [19]. Thus, care should encompass not only the children, but their caregivers and family members.

Moreover, the study participants considered spirituality and/or religiosity to be very important in their lives, and engaged in religious activities regularly. As sources of comfort, faith and hope, both factors are significant adjuvants in the care process, since they help in diagnosis acceptance and treatment adherence [5]. Religious/spiritual practices such as praying and trusting in God are frequently adopted by caregivers [22].

Similarly, a study conducted in India with 150 parents/family members of pediatric patients from different pathological contexts identified prayer as an integral component of their daily spiritual and religious ritual, aimed at recovery or improvement of the clinical picture, becoming part of the treatment [20]. In short, religiosity and spirituality emerge as a mode of situational coping much used by informal caregivers, promoting hope and comfort when facing challenges experienced in the act of caring, especially those related to children undergoing cancer treatment [5,10,19].

A first limitation regarding this study is its cross-sectional design, which does not allow to

assess cause and effect relationships. Second, the inclusion of caregivers of children undergoing treatment at a single health center may reflect a local experience, making it impossible to generalize our findings. Thus, longitudinal and multicenter research is needed.

Nonetheless, its contributions are evident, since they comprise the caregiver's experience regarding the process of caring for a child with ALL, suggesting that the use of PRSC constitutes a significant mode of situational coping, by redefining an experience often seen as purely negative. The difference, therefore, is in how they will experience this difficult situation, since the PRSC benefits include greater control of emotions. Finally, the quality of care provided to the child is directly linked to the caregivers' physical, mental, and spiritual health.

Final considerations

Informal caregivers of children with ALL predominantly use positive RSC to cope with the situational demand for care imposed on them by their child's health condition. These findings strengthen the possibility of using spirituality and/or religiosity as physical and mental well-being indicators.

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Participation of the authors
Francely Tineli Farinha designed and conducted the project, Camila Fernandes Paixão Araújo and Paula Volpe Vitorino Mucherone collected and analyzed the data, Nayara Tomazi Batista contributed to the bibliographic review and writing of the article and Armando dos Santos Trettene carried out the critical analysis and participated in the writing of the article.

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Research