

# Spiritual/religious coping and end-of-life: systematic review

*Coping espiritual/religioso e fim de vida: revisão sistemática*

*Coping espiritual/religioso y fin de vida: revisión sistemática*

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## Abstract

**Introduction:** Spirituality/religiosity is considered an essential dimension in good practices in palliative care, especially during the terminal phase. Patients, as well as their families, make use of spiritual/religious coping strategies. **Objective:** The purpose of this review was to highlight the relationship between spiritual/religious coping and terminality. **Method:** The method applied was a systematic review that used PUBMED, LILACS, BVS, PSYCINFO and SCIELO as databases. **Results:** In total, 96 articles were captured and seven were selected for analysis. These articles addressed issues about attachment, types of coping, meaning of the illness and difficulties in measuring spirituality/religiosity. **Conclusion:** Studies indicate that spiritual/religious coping influences the quality of death during the dying process.

**Keywords:** Hospice care; Adaptation, psychological; Spirituality

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## Resumo

**Introdução:** A espiritualidade/religiosidade é considerada uma dimensão essencial nas boas práticas em cuidados paliativos, principalmente durante a fase de terminalidade. Esses pacientes, assim como seus familiares, fazem uso de estratégias de *coping* espiritual/religioso. **Objetivo:** O objetivo desta revisão é mostrar a relação entre o *coping* espiritual/religioso e o processo de terminalidade. **Método:** A metodologia aplicada foi a revisão sistemática e utilizou PubMed, Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS), Biblioteca Virtual em Saúde (BVS), PsycINFO e Scientific Electronic Library Online (SciELO) como bases de dados. **Resultado:** Foram capturados 96 artigos e sete foram selecionados para análise. Tais artigos abordaram questões de apego, tipos de *coping*, significado da doença e dificuldades de mensuração da espiritualidade/religiosidade. **Conclusão:** Os estudos demonstram que o *coping* espiritual/religioso influencia na qualidade da morte durante o processo de terminalidade.

**Palavras-chave:** Cuidados paliativos na terminalidade da vida; *Coping* religioso-espiritual; espiritualidade.

## Resumen

**Introducción:** La espiritualidad/religiosidad es considerada una dimensión esencial de las buenas prácticas en cuidados paliativos, principalmente durante la fase de terminalidad. Esos pacientes, así como sus familiares, utilizan estrategias de *coping* espiritual/religioso. **Objetivo:** El objetivo de esta revisión es evidenciar la relación entre el *coping* espiritual/religioso y el proceso de terminalidad. **Método:** La metodología aplicada fue la revisión sistemática que utilizó PUBMED, LILACS, BVS, PSYCINFO y SCIELO como bases de datos. **Resultados:** Fueron capturados 96 artículos y siete seleccionados para análisis. Tales artículos abordaron cuestiones sobre apego, tipos de *coping*, significado de la enfermedad y dificultades de mensuración de la espiritualidad/religiosidad. **Conclusiones:** Los estudios indican que el *coping* espiritualidad/religiosidad influye en la calidad de muerte durante el proceso de terminalidad.

**Palabras clave:** Cuidados paliativos al final de la vida; Adaptación psicológica; Espiritualidad

## INTRODUCTION

Studies in the field of spirituality and health have grown to such an extent in recent decades that they have become a field of knowledge of their own. According to Koenig (2002), the term “religion” refers to an organized system of beliefs, practices, rituals, and symbols that brings people closer to the Transcendent. Religion is community-focused, measurable, organized, behaviorally imposing, doctrinaire. The term “spirituality” would be a personal issue, related to the search for an understanding of existential issues and/or related to the individual relationship with the Transcendent, which may or may not lead to the formation of communities or religious rituals.<sup>1</sup>

Spirituality is individual, less visible and less measurable, more subjective, less formal, not oriented toward a doctrine. Religion, when present, composes one of the expressions of individual spirituality, therefore, spirituality expression is broader than the religious one.<sup>2</sup>

Religiosity, according to the Treaty on Family and Community Medicine,<sup>3</sup> concerns the way in which people follow and practice this religion, which can be divided into organizational or extrinsic and non-organizational or intrinsic, concepts introduced by Gordon W. Allport.<sup>2</sup>

Intrinsic religiosity is related to individual practices, such as prayers and meditations. It is characterized as solid faith and is associated with the pursuit of the needs and interests of one’s own beliefs, providing motivation and meaning of life. Initially it is called mature.<sup>2</sup>

Extrinsic religiosity, on the other hand, concerns participation in the religious community and can be interpreted as a means to achieve other ends, such as when individuals participate in the community to meet people or to obtain status and security. Initially it is called immature. In this sense, extrinsic religiosity would be a way of obtaining something and intrinsic religiosity would be a personal experience.<sup>4</sup>

To talk about spiritual and religious coping (SRC), it is still necessary to define coping. The word does not have an exact translation into Portuguese, being understood as “confrontation” or “way of dealing with” by some studies. However, this translation possibly does not encompass its full meaning. Coping can be better defined as the set of strategies used by a person to adapt to adverse or stressful life circumstances.<sup>5</sup>

Coping can be directed toward the solution of a stressful situation when focused on a problem. If focused on emotions, due to a stressful cause, the objective would be to try to mitigate the negative consequences brought about by that event. “In other words, coping refers to behavioral and cognitive efforts to master, reduce, or tolerate the internal and/or external demands that are created by stressful operations” (ESPERANDIO, 2017).<sup>5</sup> In this context, prayer can be used to try to solve a problem and/or minimize emotions (anxiety). Also, participating in religious activities could be used as a way of dealing with problems, for example.<sup>5</sup>

Psychologist Kenneth Pargament transposed the concept of coping to the religious sphere, thus characterizing SRC. For him, the introduction of sacred elements helps in the response to stressful events.<sup>6</sup> In addition, Pargament characterized SRC as positive and negative in the religious sphere. Positive coping is related to the pursue of spiritual support, to the resolution of problems based on the Divine, to re-signifying stressors, to the search for help and support in sacred books, to self-forgiveness and forgiveness of others, among others. Negative coping, on the other hand, can be translated into dissatisfaction with God or the religious institution, conflicts between members of the community to which the person attends, or into the view of a punitive/very powerful Being. This would be reflected in an unstable relationship with the Divine, a superficial worldview and in suffering in the search of meaning.<sup>7</sup>

Regarding terminality, it is defined when the possibilities of patient’s health recovery are exhausted and the likelihood of a near death seems inevitable and predictable.<sup>7</sup> In this process, one must consider not only the amount of life, but its quality, mainly since it is a period characterized by the greater prevalence and intensity of physical, psychological, social, and existential issues, which makes it challenging for patients, their families and caregivers.<sup>8</sup>

In this sense, although it is not possible to change the fact that people will die, it is possible to give a different meaning to the way sick people live until the moment of their death, the way an individual dies and the memories that remain for the family.<sup>9</sup> The objective of care during this phase is, or should be, to minimize the stress of patients and their families through symptom control and supportive care, allied to the maintenance of general well-being.<sup>9</sup>

Most studies, compiled in a literature review, show that the spiritual dimension has an impact on biopsychosocial health, being associated with improved quality of life, longer survival, better mental health, greater concern for their own health and lower prevalence of diseases in general.<sup>4</sup>

Thus, religious practices can be largely related to the quality of life and death of sick people. Therefore, spirituality is central to this experience. Patients and family members seek meaning, comfort, and stress relief in the situation of illness and, thus, express their spiritual needs.<sup>10</sup>

In view of this scenario presented here, the objective of this review was to demonstrate the relationship between SRC and the dying process, based on a scientific literature review on the subject.

## METHODS

The present study was carried out based on the following investigative question: “*How can spiritual and religious coping, when present, influence the process of terminality of an ill person?*”.

This is a systematic review, which therefore has methodological rigor and selects original articles, aiming to gather information about a theme, based on scientific literature, through a specific research protocol.<sup>11</sup> Its purpose was to objectively explain information and evidence and perform an accurate synthesis of the results found. The review involves the work of at least two researchers, who independently evaluate the articles.<sup>12</sup>

This research was registered on the PROSPERO platform, under registration number CRD42020140792. This is an international database of systematic reviews in health and social work.

In addition, researchers used the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) tool, which aims to help scholars improve the reporting of the systematic review.<sup>13</sup> For this, the essential parts of a systematic review by the PRISMA checklist are confirmed, composed of 27 items that make up the research parts: title, abstract, introduction, methods, results, discussion, and funding.<sup>13,14</sup>

The PICO tool was used to formulate the research question.<sup>12</sup> Study population was defined as (P) patients in the process of terminality, intervention (I) by SRC, comparison (C) as the absence of SRC, and as expected outcome (O) the correlation of the presence of SRC with the dying process. The keywords, chosen based on the research question, were: terminality, coping, religiosity, and spirituality.

A five-year filter (January 2015 – April 2019) was adopted for data collection. The bases used were: PubMed, Latin American and Caribbean Literature on Health Sciences (LILACS), Virtual Health Library (*Biblioteca Virtual em Saúde – BVS*), PsycINFO, and Scientific Electronic Library Online (SciELO). To search for articles, the following descriptors were used: “*coping*”, “*spiritual\**”, “*relig\**”, “*terminal\**”, and “*spiritual\**”. The health sciences descriptor database (DeCS) was used in this process and the same descriptors used in the Portuguese search were translated into equivalent English and Spanish ones. The Boolean combinations used were: “*coping*” AND “*spiritual\**” AND “*relig\**” AND “*terminal\**” and “*coping*” AND “*espiritual\**” AND “*relig\**” AND “*terminal\**”.

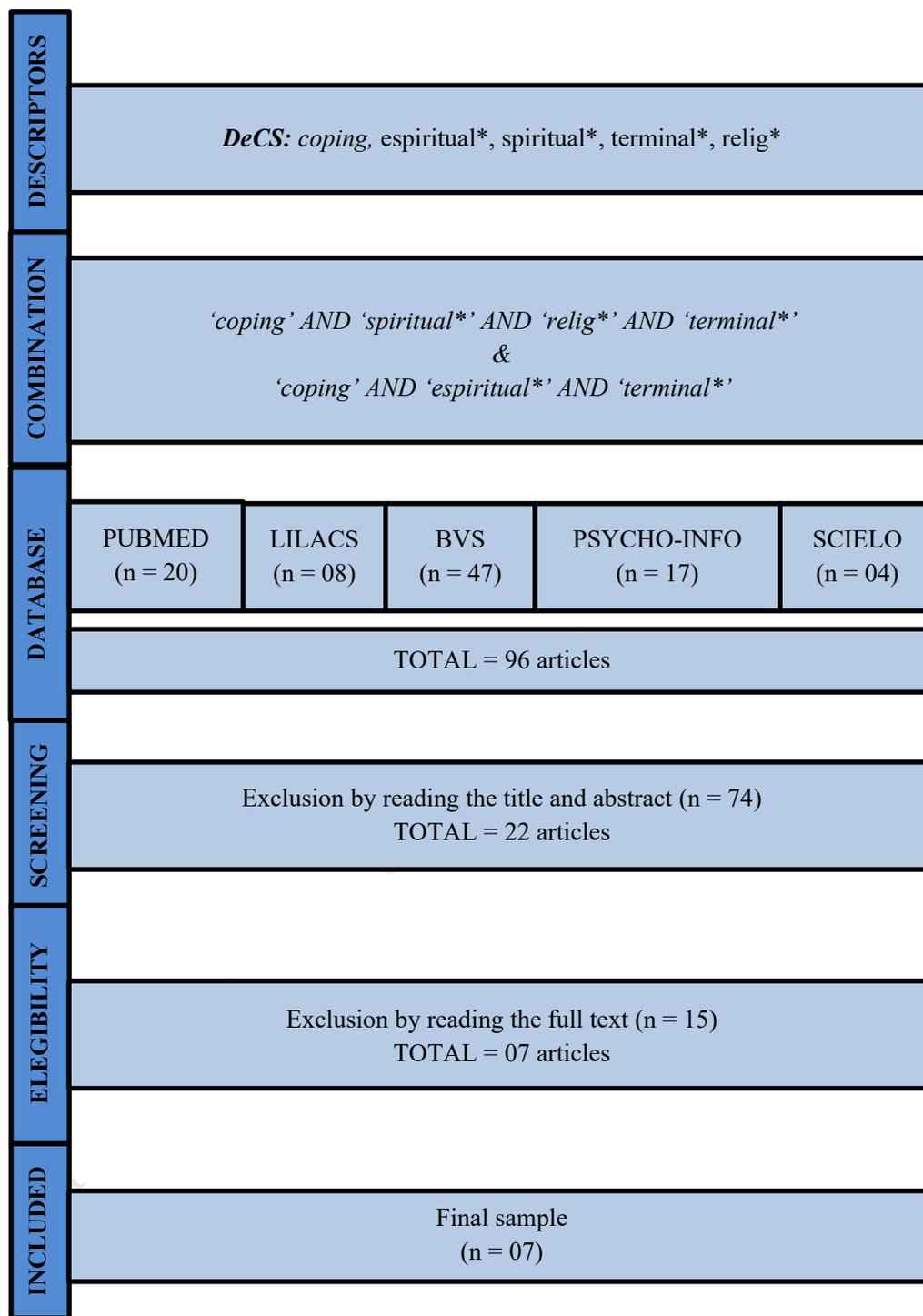
The inclusion criteria defined for the selection of articles were: articles published in any of the three languages used in the search, which, by the title and reading the abstract, answered partially or totally to the research question: “*how can SRC, when present, influence the process of terminality of an ill person?*”.

Exclusion criteria were: articles without abstracts, articles whose titles were not related to the research question, articles that, after full-text reading, did not answer the research question and articles that did not have SRC measurement or self-declaration by the patient. As a result, the authors created a flowchart of the articles’ search strategy (Figure 1).

To try to reduce the risk of bias in determining the articles chosen for the final sample, two independent searches were performed by each of the authors, which were then compared with each other. Articles with discrepancies or unusual patterns were defined by consensus by the research team.

The Risk of Bias in Systematic Reviews (ROBIS) tool was used to determine the risk of bias in the articles captured and in this systematic review.<sup>15</sup> The risk of bias occurs due to systematic errors or limitations in the design, conclusion or analysis of the review, which influence the results. This tool addresses whether the methods used in systematic reviews minimize the risk of bias in summarized estimates and conclusions and whether the research question of each review evaluated answers the research question addressed in the conducted study.<sup>15</sup>

The identification of potential risks of bias of the seven articles took into account the criteria of eligibility (domain 1), identification and selection (domain 2), data collection and evaluation (domain 3), and synthesis and results (domain 4) of studies. Thus, three of them were considered to have a low risk



Source: authors, 2019

**Figure 1.** Article search strategy flowchart

of bias, as they obtained, in the domains, only an uncertain classification and the others were low; and four had intermediate risk, as they obtained two domains classified as uncertain (BRASIL, 2017). The risk of bias of this systematic review was also formally assessed by the ROBIS tool, resulting in a systematic review with low risk of bias.

## RESULTS

The search resulted in the initial capture of 96 articles. After pre-selection by title and abstract and full text reading, seven works were selected for analysis. These surveys were tabulated by number, year, author/title, type of study/participants, location and a brief summary of the main findings (Table 1). Excluded articles addressed chronic diseases, outside the dying process; reported the importance of spirituality/religiosity (S/R), without relating it to coping; or the researched public did not consist of patients.

The total number of participants in the seven studies were 842 patients, who had diseases such as cancer in the process of terminality, chronic kidney disease on hemodialysis, progressive and terminal diseases, and patients in palliative care.

**Table 1.** General data of the final sample articles.

No.	Year	Author/Title	Type of Study/ No. of participants	Location	Main findings
1	2019	Balboni TA, Prigerson HG, Balboni MJ, Enzinger AC, Vanderweele TJ, Maciejewski PK. A scale to assess religious beliefs in end-of-life medical care.	Observational, longitudinal study with 374 participants with cancer	USA	The Religious Beliefs in the End-of-Life Medical Care scale shows a positive association with patients' spiritual and religious indicators. It also addresses the inverse relationship with the understanding of terminally ill patients and their acceptance, which elucidates their clinical potential and promotes informed decisions in the end-of-life context.
2	2018	Kunsmann-Leutiger E, Loetz C, Frick E, Petersen Y, Müller JJ. Attachment Patterns Affect Spiritual Coping in Palliative Care.	Cross-sectional and correlative design, with 80 participants with cancer and terminal illness.	Germany	Research has shown association with attachment patterns and spiritual coping. Thus, knowing which attachment patterns influence spiritual coping contributes to the quality of life in terminally ill patients.
3	2018	Selman LE, Brighton LJ, Sinclair S, Karvinen I, Egan R, Speck P, Powell RA, Deskur-Smielecka E, Glajchen M, Adler S, Puchalski C, Hunter J, Gikaara N, Hope J. Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries.	Qualitative focus group study, with 74 participants with progressive diseases and in the process of terminality.	United Kingdom	The results reveal that preferences about spiritual coping, both of patients and caregivers, are important for the quality of patients' connection with health professionals.
4	2016	Moestrup L, Hvidt NC. Where is God in my dying? A qualitative investigation of faith reflections among hospice patients in a secularized society.	Participant observation with a qualitative approach, with 17 participants	Denmark	The conclusion shows that patients, despite being hesitant to share their faith with health professionals about their condition, demonstrate the importance of having faith, even though they do not have much knowledge about the subject or religious practice.

Continue...

**Table 1.** Continuation.

No.	Year	Author/Title	Type of Study/ No. of participants	Location	Main findings
5	2015	Nilmanat K, Promnoi C, Phungrassami T, Chailungka P, Tulathamkit K, Noo-Urai P, Phattaranavig S. Moving beyond suffering: the experiences of Thai persons with advanced cancer.	Longitudinal qualitative case study, with 15 participants with terminal cancer	Thailand	During the interviews, three themes were addressed: adopting a religious doctrine, being hopeful and surrounded by loved ones or family members. In this way, the study shows the roles of faith and spirituality in overcoming suffering for Thai patients during the dying process.
6	2017	Santos PR, Capote Júnior JRFG, Cavalcante Filho JRM, Ferreira TP, Santos Filho JNG, Silva Oliveira S. Religious coping methods predict depression and quality of life among end-stage renal disease patients undergoing hemodialysis: a cross-sectional study.	Cross-sectional study, with 161 hemodialysis participants	Brazil	The results show that there is evidence to suggest that spiritual/religious coping may be associated with quality of life and depression among hemodialysis patients.
7	2015	Barreto P, Diego R; Galiana L, Oliver A, Fombuena M, Benito E. Bienestar emocional y espiritualidad al final de la vida / Emotional and spiritual well-being at the end of life.	Descriptive cross-sectional, with 121 patients in palliative care	Spain	The conclusions point to evidence of the importance of spirituality for the well-being of patients.

Source: the authors, 2020

The scales used in the quantitative studies were: Religious Beliefs in End-of-Life Medical Care (RBEC); Religious Coping Questionnaire (RCOPE), Center for Epidemiologic Studies Depression (CES-D), Medical Outcomes Study 36-Item Short Form Health Survey (SF-36), Hospital Anxiety Depression Scale, Brief Resilient Coping Scale, Edmonton Symptom Assessment System.

These scales address spiritual and psychosocial issues and how they influence the patient's understanding of terminality (RBEC); make it possible to estimate the frequency of coping, differentiating it into positive and negative (RCOPE); assess the presence or absence of depression in patients (CES-D); measure the interviewees' quality of life (SF-36); assess anxiety and depression (Hospital Anxiety Depression Scale); measure patients' resilience (Brief Resilient Coping Scale); and, finally, they assess the intensity of their symptoms (Edmonton Symptom Assessment System).

The questionnaires used in the qualitative research by Elke Kunsmann-Leutiger et al., to determine attachment patterns and to assess patients' different spiritual coping strategies, were: Adult Attachment Projective System (APP) and Spiritual and Religious Attitudes in Coping with Illness (SpREUK). In addition, the questionnaire used in the research by Pilar Barreto et al., prepared by the Grupo de Espiritualidad, was useful to assess spirituality as intrapersonal, interpersonal, and transpersonal. The experience indicators used in the same survey to measure patients' feelings of help, concerns and greatest fears were developed by a multidisciplinary panel, using tools from the Spanish Society of Palliative Care (SECPAL).

The surveys were carried out in 14 countries: the United States, Brazil, the United Kingdom, Denmark, Thailand, Germany, Spain, Canada, South Africa, Kenya, South Korea, Belgium, Finland, and Poland. Most articles included neoplasms as the main disease in terminally ill patients. In the

sociodemographic analyses carried out in the selected articles, the following religions/beliefs were cited: Catholicism, Protestantism, Buddhism, Baptist, Judaism, another branch of Christianity, without affiliation, agnosticism/atheism, Islamism, spiritualized and non-religious, without belief in the system, Lutheranism and others not specified.

## DISCUSSION

The selected articles are permeated by issues related to the construction of attachment, to positive and negative coping, to the way of attributing meaning to the illness and to difficulties of measuring the spiritual/religious dimension of patients in the end-of-life scenario, which will be addressed next.

The construction of attachments, at birth, could be linked to the way we connect with the spiritual/religious sphere at the end of life (attachment theory vs. spirituality/religiosity). These attachment patterns are “activated” in scenarios of intense stress or separation, such as in cases of serious, possibly fatal, illness. Different patterns related to SRC were identified, which affected the quality of life and death of patients in the process of terminality. Patients with anxious attachment type scored lower on the SpREUK scale, indicating little relationship with spiritual coping (little attribution of meaning to life), unlike other attachment patterns (securely, dismissively, and unresolved), which showed high scores on the SpREUK scale.<sup>16</sup>

In Thai culture, the diagnosis of cancer, for patients, is synonymous with death. This vision refers to reflections on the connection of body and mind; coping strategies during the dying process; the justification of illness by karma, the acceptance of inevitable and inherent aspects of life, and tam jai (Buddhist term used to refer to the way of dealing with daily obstacles and moving forward). These reflections allow the consolidation of three pillars that permeate the dying process of Thai patients: hope, presence of loved ones, and care for family members. They demonstrate association with overcoming suffering, allowing for positive feelings of harmony and peace at the end of life. The importance of approaching these pillars by health professionals is also highlighted, in a sensitive way and according to patients’ individual S/R and their culture.<sup>17</sup>

In contrast to the study by Nilmanat et al., patients from a Danish hospice stated that there is no need to approach SRC in any situation by the health team, as it is seen as belonging to the individual and restricted to their personal sphere. For these patients, this approach becomes relevant and welcome, particularly when there are signs of religious pain and suffering. Even in this individual and particular context, the importance of the S/R dimension is recognized by them.<sup>18</sup>

The study by Selman et al., which questions existential, psychological, religious, and social aspects in 11 countries through focus groups, reaffirms the importance of dimensioning S/R, already raised in the study by Moestrup and Hvidt. However, in this research, unlike what happened in the study with Danish patients, the approach of spirituality/religiosity was identified as important and not restrictive to health professionals and/or caregivers, demonstrating that the choice of the most appropriate person to deal with the matter depends solely on patients and the skill of health professionals.<sup>19</sup>

However, the study by Nilmanat et al. (2015) is in line with the findings of the article entitled “*Religious coping methods predict depression and quality of life among end-stage renal disease patients undergoing hemodialysis: A cross-sectional study*”, in which positive SRC represented an improvement in the quality of life and vitality of patients. This article correlated, using three scales, SRC, depression, and quality of life in Brazilian patients with end-stage renal disease. The results

demonstrated that negative SRC is more influential in depressed patients, with low mental health scores and impaired social function. In addition, the higher the positive SRC scores, the higher the indices related to general health and vitality, which, according to the authors, reinforces the approach to spirituality/religiosity in this context.<sup>20</sup>

Corroborating Santos et al., the article “*Bienestar emocional y espiritualidade al final de la vida*” addresses a group of patients only in palliative care, with an average age of 67 years, and states that spirituality is not only a need for patients, but also a modulator of their emotional well-being.<sup>21</sup>

Regarding the characterization of the spirituality of sick people, there is some difficulty in framing it in a study tool, as it is individualized and personal. In the end-of-life scenario, the relationship built between patients and their religious beliefs, when present, is unique and can interfere with therapeutic decisions. In such a context, tools that serve to assess the interrelationship between religion, spirituality, therapeutic decisions and care can be useful.<sup>22</sup> This is the case of RBEC and others used to analyze aspects of S/R in studies of this systematic review.

## CONCLUSION

The analyzed studies indicate that SRC influences death quality during the dying process. In this sense, health team relevance is evident to recognize the need to address this issue and the presence of family or loved ones in the terminal phase. It is therefore essential that health care professionals identify the degree of importance given by patients to spiritual/religious issues, since there is evidence on the impact that this dimension will have at the end of life.

Although the sample size of the studies is quite varied, it is difficult to generalize the results, since, as SRC is a biopsychosocial and spiritual construction, it becomes specific to the group studied.

The limitation of this study is the small number of articles that deal with the relationship between SRC and terminality from patients' perspective. In addition, as the spiritual and religious dimension has a comprehensive measurement, it is difficult to establish an ideal methodology for the expected objectives, both in studied population size and in the bias given to the research (for example, relating coping with mental health or spirituality/religiosity).

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## CONFLICT OF INTERESTS

Nothing to declare.

## AUTHORS' CONTRIBUTION

VCAV: Conceptualization, Data Curation, Formal Analysis, Writing – Original Draft, Writing – Review & Editing. ALPR: Conceptualization, Data Curation, Formal Analysis, Writing – Original Draft, Writing – Review & Editing. ERR: Conceptualization, Data Curation, Formal Analysis, Writing – Original Draft, Writing – Review & Editing. MJA: Conceptualization, Data Curation, Formal Analysis, Writing – Original Draft, Writing – Review & Editing. MRGE: Conceptualization, Data Curation, Formal Analysis, Writing – Original Draft, Writing – Review & Editing

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