## Palliative and Supportive Care

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## **Review Article**

Cite this article: Rossato L, Benfato JC, Ullán AM, Scorsolini-Comin F (2022). Religious-spiritual experiences of family members and caregivers of children and adolescents with cancer. *Palliative and Supportive Care* 20, 711–719. https://doi.org/10.1017/S1478951521001590

Received: 3 June 2021 Revised: 20 July 2021 Accepted: 6 September 2021

#### Key words:

 ${\it Cancer; Children; Family; Religiosity;}$ 

Spirituality

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## Religious-spiritual experiences of family members and caregivers of children and adolescents with cancer

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#### **Abstract**

This integrative literature review aimed to identify the religious and spiritual experiences of family members and caregivers of children and adolescents with cancer. Through systematized searches in the databases/libraries CINAHL, PsycINFO, Pubmed, SciELO, and Lilacs, 69 articles produced between 2010 and 2020 were retrieved. There was a predominance of studies with parents developed in hospital facilities. The caregivers' religious and spiritual experiences helped them to cope with childhood cancer, especially in maintaining hope, reducing stress and anxiety symptoms, as well as in providing psychological and social support. Negative outcomes such as questioning faith, the feeling of punishment, and disruption with the religious and spiritual group were also perceived. It is recommended to include religiosity and spirituality for the provision of more humanized and comprehensive care, as well as further investigation of the negative experiences regarding religiosity and spirituality in this public.

### Introduction

Every year, about 400,000 children and adolescents are diagnosed with cancer worldwide, being a public health problem, especially in developing countries [Schüz and Roman, 2021; World Health Organization (WHO), 2021]. As it is generally not possible to prevent cancer in children, the most effective strategy is to focus on an immediate and correct diagnosis, followed by effective evidence-based therapy, with personalized supportive care (WHO, 2021).

The World Health Organization (WHO) estimated for the year 2020 the appearance of approximately 26,467 new cases of cancer in children aged 0–19 years in Europe, 62,776 in the African continent, 29,057 in Latin America and the Caribbean, 143,053 in Asia, 1879 in Oceania, and 16,187 in North America (World Health Organization, 2020). In Europe, childhood cancer mortality has decreased remarkably, but it is still possible to observe disparities between Eastern and Western regions (Gatta et al., 2014; Bertuccio et al., 2020). However, although childhood cancer mortality has declined in Europe, action is still needed to ensure that all European children have equal access to early diagnosis and effective treatment (Bertuccio et al., 2020).

Even with the several advances concerning available treatments, the psychological impacts remain high due to the adverse effects of treatment and the implications on the individuals' and their families quality of life (Bakula et al., 2020). Cancer diagnosis in childhood and adolescence can interfere with the dynamics of family functioning, with repercussions on physical and psychological health, socioeconomic and behavioral aspects, among others (Schoors et al., 2019; Toledano-Toledano et al., 2019).

Having a child/adolescent with cancer affects the parents' lives and may bring short- and long-term challenges to the family environment, affecting the activities routine that becomes centered on the child/adolescent that needs assistance (Moghaddasi et al., 2018; Tan et al., 2020). Thus, family members and caregivers must adapt themselves to a routine of assistance and uncertainty, and possibly develop resources capable of coping with this condition.

The fact that sick people are at the beginning of their lives, as well as how they will react and cope with the treatment, are elements that will influence future perspectives, dreams, and hopes that they had before getting sick. Thus, it can be seen that cancer is a complex phenomenon and because it affects people in a sensitive period of development it raises several medical, psychological, ethical, and social concerns due to the different kinds of impacts it may cause (Steliarova-Foucher et al., 2017).

Along with accompanying their children's painful process, parents must deal with increased parenting responsibilities and manage the treatment demands. Besides, these family members may experience moments of overload that impact overall health conditions, especially mental

ones (Wang et al., 2017). Thus, caregivers and family members are affected in several dimensions of their lives for playing the essential role in accompanying the diagnosis's trajectory to the treatment phase, assisting in coping with the disease, and adapting to the difficulties that arise over time.

To face these challenges about the illness, caregivers and family members use several coping strategies. Among them, religiosity/ spirituality (R/S) has been increasingly highlighted. Religion, religiosity, and spirituality are important dimensions in people's lives in most sociocultural contexts. Due to the importance they assume and the influences they exert on subjectivity, they have been evidenced in the scientific literature as influencing health conditions and received different descriptions and concepts, being of particular interest to the health sciences (Cunha et al., 2020).

Religiosity can be characterized as a set of beliefs and practices associated with a recognized religion or denomination. Spirituality is generally recognized as a dimension that involves experiential aspects, which may be related to religious practices or the recognition of a general sense of peace and connection (Proserpio et al., 2014). When these terms are discussed as coping strategies, the term R/S is used (Rossato et al., 2021). This term allows emphasizing the effects of these resources on health and not the epistemological specifics of each expression.

Religious and spiritual practices are present in all cultures, being markers that influence the ways of life and the relationships established among people (Rossato et al., 2021). In cases of childhood cancer, R/S has been described as a resource that accompanies the family/caregivers in the illness itinerary, contributing to resilience, emotional adjustment, and interfering in decision making (Lion et al., 2019).

Because it is a cultural component present in most social contexts, R/S presents itself as a significant subjective resource for the experiences of family members and caregivers and can interfere positively and negatively in the way these individuals will deal with their children's disease. R/S can offer conditions to deal with uncertainties, stressful and anxiogenic situations to live with, and to accept the disease. However, it can also be a component that generates discomfort, detachment, and anger toward what is being experienced (Abdoljabbari et al., 2018).

Religious and spiritual care has been offered to people who experience situations of illness due to cancer in different contexts of health care by chaplains and other qualified professionals. A study developed by Proserpio et al. (2016) showed, for example, that in Italy 24 out of 26 health centers investigated had a spiritual support service, while in Spain 34 out of 36 health centers provided this care. Also according to the authors, the care provided involved offering religious services, celebrating rites, providing spiritual support in the terminal phase of the disease, talking to family members and adolescents. Despite this, it is important to consider that, although R/S is a dimension present in most social contexts, it can vary depending on the culture in which people are inserted, being more valued in some places than in others.

In the context of religious and spiritual care, the chaplain plays a significant role among members of the healthcare team providing support for children and adolescents with cancer, their families and other pediatric oncology professionals. In this sense, they must be seen as an integral part of the hospital team, offering support and monitoring throughout the various stages of the disease, the treatment of patients and a presence that must be constant in the hospital, not only requested in critical situations (Proserpio et al., 2014).

Considering these aspects, it is evident that R/S is a resource that needs to be considered in the health practices developed in Pediatric Oncology, understanding how it involves people's experiences that accompany the assistance. Based on this need and aiming at the construction of practices that consider R/S from the point of view of shreds of evidence, this integrative review of scientific literature aimed to identify the religious and spiritual experiences of family members and caregivers of children and adolescents with cancer.

#### Method

This is an integrative review of scientific literature regarding the period from January 2010 to December 2020. The choice of this period was because it only covers complete years, as well as providing a snapshot of the last decade. The review considered the Preferred Reporting Items for Systematic Reviews and Meta-Analyze Protocols (PRISMA; Moher et al., 2010) recommendations for systematic searching, analysis, and description.

The guiding question was developed using the PICO strategy (Population, Intervention, Comparison, and Outcomes/Outcome). Based on the review objective, the comparison criterion was not used in the present study. Thus, the guiding question was constructed as follows: "How has the scientific literature described R/S experiences of family members and caregivers of children/adolescents with cancer?"

The data survey was carried out in Scientific Electronic Library Online (SciELO), Latin American and Caribbean Health Sciences Literature (LILACS), Cumulative Index to Nursing and Allied Health Literature (CINAHL), National Library of Medicine [USA] (Pubmed), and Psychology Information (PsycINFO) databases/libraries. The descriptors used in Portuguese, English, and Spanish were previously consulted in these databases and combined as follows: (religiosity OR religion OR spirituality OR spiritual OR faith OR religious coping OR spiritual coping) AND (parents OR family OR families OR caregivers) AND (child OR children OR childhood OR adolescent OR adolescents) AND (neoplasms OR cancer OR tumor OR oncology).

The inclusion criteria established were: (a) articles published between January 1, 2010 and December 31, 2020; (b) written in English, Portuguese, or Spanish; (c) population: family members (e.g., father/mother, uncle/aunt) and caregivers of children and adolescents with cancer; which focused on the use of R/S in personal and caregiving experiences; and (d) available for reading in their entirety. The exclusion criteria were (a) theses, dissertations, books, book chapters, literature reviews, and studies of theoretical nature; (b) articles that did not fit the theme; (c) with focus on a population other than family members and caregivers; (d) repeated; (e) in a language different from the inclusion; and (f) articles that did not allow answering the guiding question.

After conducting the searches, the results found were entered into the Rayyan software (Ouzzani et al., 2016). This software is used to organize, analyze, and systematically select the review results. The shreds of evidence analysis occurred by two independent judges and in cases of disagreement, a third judge decided on the inclusion or exclusion. The first judge is a female graduate student in nursing with experience in literature review procedures, the second judge is a doctoral student with experience in the subject and these procedures, and the third judge is the research supervisor. The information collected was previously defined by the authors [LR] and [FS-C] considering the objectives of the study and the PRISMA checklist. A standardized form was established

by the first author to enter the information of the selected articles, being: authors, year of production, and nationality of the institution they were linked to, location of the studies, the population involved, and how the R/S was described/used by the participants.

## **Findings**

The final sample was composed of 69 articles. Figure 1 shows the flowchart with the study selection steps, the number of articles

found in each database/library, the exclusions, and the reasons for the exclusions.

After establishing the final number of articles that met the inclusion and exclusion criteria, data extraction was carried out by the researchers. Through data analysis and interpretation, three categories were created: (1) Profile of the studies; (2) Positive aspects of R/S for family members and caregivers in coping with cancer; and (3) Negative aspects of R/S in the experiences of family members/caregivers.

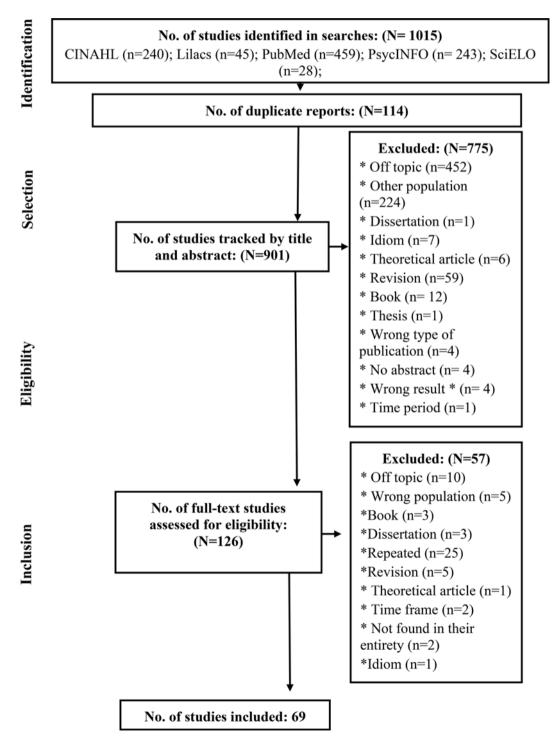


Fig. 1. Flowchart of survey and selection of articles.

#### Profile of the studies

The time frame that was chosen in this review comprised the studies produced between the years 2010 and 2020. The largest number of articles was published in the year 2018 (11 articles), followed by 2019 (nine articles), 2014 and 2020 (both with eight articles), 2010, 2013, and 2016 (both with six articles), 2015 and 2017 (with five articles each), 2012 (with three articles), and 2011 (with two articles).

Regarding the institutions' nationality to which the authors were related, the country that presented the most studies was Brazil (14 articles), followed by Iran (n = 12) and the United States (n = 11). The other countries were Canada and Lebanon (three articles each), Singapore, India, Turkey, and Taiwan (two articles each), Venezuela, Mexico, Spain, Colombia, Jordan, Indonesia, Zambia, Netherlands, Australia, and Israel (one article each). Studies also included inter-institutional partnerships between Canada and Israel (two articles), the United States and Canada (one article), Italy and Portugal (one article), the Netherlands and England (one article), El Salvador and the Netherlands (one article), Ghana and England (one article), and Australia and Iran (one article).

Regarding the participants of the studies, there were mothers, fathers, grandparents, siblings, health professionals, children, adolescents, and caregivers. Mothers and fathers were the most prominent participants (in 22 articles), followed by studies that presented only mothers (n = 18), fathers (n = 4), fathers, mothers, and children (n = 4), relatives (n = 3), caregivers (n = 2), family caregivers (n = 2). Studies with the following nomenclatures had one article each: caregivers and survivors; fathers and patients; mothers and health professionals; caregivers; fathers, mothers, and siblings; children, doctors, mothers, and fathers; caregiver and mothers; children and mothers; grandparents; family members and caregivers; adolescents and caregivers; mothers and informal caregivers; caregivers and key informants; family members and health team.

Regarding the locations, the hospital was the environment most evidenced as the field of research (in 53 articles), followed by support homes (n = 2) and studies that did not specify exactly the environment in which they were developed (n = 2). The other environments had one article each: pediatric oncology center; specialized center; place chosen by the participant; pediatric hematology and oncology unit; support group and volunteer associations; Non-Governmental Organization; participant's home or workplace; cancer support institute; tertiary care unit; tertiary treatment center; medical center; inpatient unit; and ambulatory facility.

## R/S positive aspects for family members and caregivers in coping with cancer

R/S was described as a dimension that can influence positively and negatively in the lives of people who are following the treatment process of childhood cancer, as well as by the subjects who are ill. Regarding the positive aspects, R/S was described mainly as a strategy used for maintaining hope, offering emotional support, motivating belief in divine power, maintaining positive feelings and thoughts, motivating the adoption of religious and spiritual practices as a form of comfort in difficult moments, a source of social support, in reducing psychopathological symptoms, in adapting to the reality being experienced, and in acceptance.

It was also evidenced that R/S helps in emotional balance, stress management, quality of life, strengthening family bonds,

as a form of self-care, as a source of balance and wellness, as a source of support, in life satisfaction, is a source of optimism, positive influence on mental health motivates the adoption of positive attitudes, attenuates the suffering experienced, is a source of information, awakens feelings of gratitude, among others.

# Negative aspects of R/S in the experiences of family members/caregivers

R/S negative aspects were mainly linked to the questions and reflections about the parents' reasons or attitudes that could have triggered the appearance of illness in children and adolescents. In this sense, the studies presented data that showed parents' perceptions that the illness could be linked to divine intervention in their son/daughter's health. There were also situations in which the illness caused distancing from the religious/spiritual community to which they belonged and the weakening of beliefs.

The main negative aspects recovered in these studies were: the questioning faith, the blame, the break with the religious/spiritual group due to lack of support, the shaken faith (disbelief, reduction of religious/spiritual practices, and abandonment feeling), belief in a vengeful God, believe that the disease would be divine punishment, enhancement of psychopathological symptoms, religious and spiritual struggles. These aspects prove that, although R/S is a positive factor in facing cancer, it can also interfere negatively in the lives of family members/caregivers and be one of the factors that contribute to this population's psychological illness.

Figure 2 summarizes the main aspects observed in the articles of the final sample through authorship, year and country of authors, place of accomplishment, participants, and main aspects of the described R/S. Due to the amplitude of the retrieved material, this article will present a synthesis of the main contents related to R/S presented in the studied findings.

## **Discussion**

The data found in this integrative review bring a significant picture of the profile of scientific productions and how the experience of family members and caregivers who accompany the children and adolescents' treatment with cancer are affected by the patients' experiences. Although the focus of this review was to analyze how family members and caregivers experience the family members and caregivers in the process of cancer care, health professionals and the sick children and adolescents themselves were also the targets of the studies and, for this reason, considered in the analysis.

The results showed a significant number of articles published in recent years that sought to analyze the impacts of R/S on the lives of family members and caregivers. These studies reflect that R/S has been considered important to be investigated in its relationships with the population health aspects. The data presented show the need to understand human development as multidimensional and to consider the concept of health as a biopsychosocial and spiritual dimension as described by the World Health Organization (WHO, 1998). The growing number of studies focused on the R/S investigation demonstrates a positive tendency to consider the subjects in their entirety and not as mere biological beings, thus evidencing a possible overcoming of the biomedical model that predominated in the health field.

The variety of nationalities of the institutions to which the authors were linked demonstrates that this theme has been investigated globally, especially in contexts where religion, religiosity,

Authors, authors' year, and	Local	Sample	How R/S was described/used by the participants	DOLURL
Faria and Cardoso (2010).	Hospital	F. M	Belief in divine power, maintaining hope, acceptance.	http://dx.doi.org/10.1590/S01
Brazil. Zelcer et al. (2010). Canada.	Hospital	F. M	Maintaining hope, belief in divine power.	03-166X2010000100002 https://doi.org/10.1001/archp ediatrics.2009.284
Di Primio et al. (2010). Brazil.	Hospital	FM	Rupture with the church due to lack of support, questioning faith, belief	ediatrics 2009;284 https://doi.org/10.1590/S0104 -07072010000200015
Fletcher et al. (2010). Canada.	Hospital	M, HT	in divine power, helping emotional balance, strengthening family ties.  Maintaining positive feelings and thoughts, emotional support.	https://doi.org/10.1177%2F1
Lin et al. (2010). United States.	Hospital	F, M	maintaining hope,  Emotional support increased religious and spiritual practices.	043454209360839 https://doi.org/10.1016/j.ijnur
Wegner and Pedro (2010).	Hospital	Cr	Emotional support, maintenance of hope, R/S as a form of self-care,	stu.2010.05.009 https://doi.org/10.1590/S1983
Brazil. Banerjee et al. (2011). Canada.	Pediatric	Cr	source of balance, and well-being.  Coping resource, source of support, increased religious and spiritual	-14472010000400010 https://doi.org/10.1177%2F1
Fuenmayor and Chacin (2011).	Oncology Centers Hospital	F	practices, maintaining hope, questioning faith.  Source of emotional support, coping resource, positive reinterpretation	043454211408106
Venezuela. Gilmer et al. (2012). United	Hospital	F. M. B	of life.  Source of comfort, adoption of positive attitudes, shaken faith.	http://www.redalyc.org/artics lo.oa?id=375634868002 https://doi.org/10.1016/j.jpain
States and Canada. Barón and Rubio (2012). Spain.	Hospital	F.M	Maintenance of hope increased religious and spiritual practices.	
Dupas et al. (2012). Brazil.	Specialties Center	F	Source of emotional balance, maintaining hope.	http://dx.doi.org/10.5209/rev PSIC.2012.v9.n1.39136 http://reme.org.be/artigo/deta/
		F, M	Source of emotional manage, maintaining hope.  Belief in divine power, maintaining hope, maintaining positive thoughts.	hes/537
Chinchilla-Salcedo (2013). Celombia. Arabiat et al. (2013). Jordan.	Chosen by the attendee			https://dialnet.unirioja.es/serv let/articulo?codigo=4955955
	Hospital	М	Questioning faith, guilt, and adoption of religious/spiritual practices seeking help.	let/articulo?codigo=4955955 https://doi.org/10.1177942F1 043659613481808
Perricone et al. (2013). Italy and Portugal.	Pediatric Hematology and	М	Emotional support, maintaining positive thoughts, social support.	https://doi.org/10.4081/pr.20/ 3.e11
Barrera et al. (2013). Canada	Oncology Units Hospital	F	Maintaining hope.	https://doi.org/10.1097/NCC.
and Israel.  De Vries et al. (2013).	Hospital	F, M,	Emotional support, maintaining hope, adopting religious/spiritual	0b013e318291bu7d https://dei.org/10.1080/21507 716.2012.757254
Netherlands. Hensler et al. (2013). United	Hospital	C, HT	practices seeking help.  Strengthening R/S, increasing religious and spiritual practices, maintaining hope, questioning faith.	716.2012.757254 https://doi.org/10.1177%2F1 043454213487435
States. Almico and Faro (2014). Brazil.	Support Group and Volunteer	M, Cr	maintaining hope, questioning faith.  Coping resource, emotional support, the form of self-care, maintaining	
	and Volunteer Association		hope.	psd150313
Wakefield et al. (2014). Australia.	Hospital	G	Source of social support.	https://doi.org/10.1002/pon.3 513
Reisi-Dehkordi et al. (2014). Iran	Hospital	M, C	Questioning faith, belief in a vengeful God, illness as divine punishment.	https://www.ncbi.nlm.nih.go/ /pmc/articles/PMC4145485/
Kudubes et al. (2014). Turkey.	Hospital	F, M, C	Questioning faith and bound to the conditions of improvement or worsening of the sick person's health conditions.	http://dx.doi.org/10.7314/AP CP.2014.15.8.3487
Kanda et al. (2014). Brazil.	Hospital	FM	worsening of the sick person's health conditions.  Adaptation, maintaining hope, belief in divine power.	http://www.redalyc.org/articu lo.ou?id=483647660012
Neu et al. (2014). United States.	Hospital	М	Adoption of religious/spiritual practices seeking help, emotional	https://doi.org/10.1016/j.pedr
Araujo et al. (2014). Brazil.	Non-	М	support, maintaining hope.  Adaptation, acceptance, maintaining hope, emotional support,	.2014.01.002 https://doi.org/10.5205/1981-
	Governmental Organization	-	alleviation of suffering.	8963-v8i5a9798p1185-1191- 2014
Sélos et al. (2014). Brazil.	Support House	М	A coping strategy, stress management, maintaining hope, adaptation, acceptance, emotional support.	http://dx.doi.org/10.5205/reu ol.5876-50610-1-
Al-Gharib et al. (2015).	Hospital	F, M, C	Source of support.	SM.0806201404 http://dx.doi.org/20.3978/j.isc
Lebanon. Abu-Raiya et al. (2015). Israel.	Hospital	F, M	Coping resource, satisfaction with life.	n.2224-5820.2015.01.04 https://doi.org/10.1093/hsw/t lv031
Dantas et al. (2015). Brazil.	Support House	F, M	Coping resource, sansaction with the.  Coping resource, belief in divine power, maintaining hope, adaptation,	
Transk many		-1-4	coping resource, better in covine power, maintaining tope, acaptation, and acceptance.	6817-60679-1- ED:0901201519
van der Geest et al. (2015).	Hospital	F, M, C	Emotional support, coping resource, maintaining hope.	https://doi.org/10.1089/jpm.2 014.0287
Netherlands and England. Rossel et al. (2015). El Salvador	Home or	F. M	Belief in divine power, maintaining hope, social support, maintaining	https://doi.org/10.1016/j.ejon
and Netherlands. Alves et al. (2016). Brazil.	workplace Cancer Support	FM, Cr	positive thoughts.  Emotional support, maintaining hope, belief in divine power, source of	2015.01.005 https://doi.org/10.1590/0104
Beheshtipour et al. (2016). Iran.	Institute Hospital	F. M	confidence.  Mitigation of psychopathological symptoms.	07072016002120014. https://www.ncbi.nlm.nih.go/
Renner and McGill (2016).	Hospital	F, M	Coping resource, source of information, alternative complementary	/pmc/articles/PMC4709819/ http://dx.doi.org/10.4314/gm
Ghana and England. Wilson et al. (2016). United	Unspecified	F.M.	resource, belief in divine power.  Emotional support, attenuation of psychopathological symptoms.	.v50s3.6 https://doi.org/10.1002/jts.22
States. Nikseresht et al. (2016). Iran.	Hospital	М	Emotional support, positive influence on mental health.	123 https://doi.org/10.1097/HNP. 00000000000000175
Cornelio et al. (2016). India.	Hospital	м	Maintaining hope, belief in divine power, belief in a vengeful God,	0000000000000175 https://doi.org/10.4103/0973-
Gardner et al. (2017). United	Tertiary Care	Cr	adoption of religious spiritual practices seeking help.  Social support, source of optimism, maintaining hope.	1075.179608 https://doi.org/10.1002/pon.4
States. Freitas et al. (2017). Beazil.	Unit Hospital	M, Cr	Maintaining hope, belief in divine power, adaptation, acceptance,	014 https://doi.org/10.4025/psicol
		7.54	emotional support, adoption of religious spiritual practices seeking help, questioning faith, rebelling against God.	estud.v22i3.34606
Nicholas et al. (2017). Canada and Israel.	Hospital	F, M	Belief in divine power, maintaining hope, emotional and social support, adaptation, acceptance, adoption of religious/spiritual practices seeking	https://doi.org/10.1080/07347 332.2017.1292573
Doumit and Khoury (2017).	Testion Costs	F. M	help, shaken faith.	https://doi.org/10.1080/07347
Lebanon. Nikfarid et al. (2017). Iran.	Tertiary Center	M M	Belief in divine power, maintaining hope, acceptance, adaptation.	
	Hospital	Cr	Belief in a vengeful God, illness as divine punishment, maintaining hope, emotional support.	https://doi.org/10.1016/j.ejon 2017.02.003
Vitorino et al. (2018). Brazil.	Hospital	50	Questioning faith, potentiation of psychopathological symptoms, religious and spiritual struggles.  Illness as divine punishment, questioning faith, vengeful God,	https://doi.org/10.1002/pon.4 739
Nikfarid et al. (2018). Iran.	Hospital	м	adaptation, acceptance, maintaining hope, adoption of religious/spiritual	https://doi.org/10.1177%2F1 043454217748597
Chivukula et al. (2018). India.	Hospital	F, M	practices seeking help.  Ilmotional support, burden reduction, coping resource, and improved	https://doi.org/10.4103/IJPC.
Atashzadeh-Shoorideh et al.	Hospital	F, M	wellness.  Reduced faith, shaken faith, questioning faith, social support, adoption	JPC 209 17 https://doi.org/10.4103/jfmpc
(2018). Iran. Cutillo et al. (2018). United	Hospital	F, M	of religious/spiritual practices seeking help.  Adaptation, acceptance, belief in divine power, maintaining hope.	jfmpc_76_18 https://doi.org/10.3171/2018.
States. Sheikhzakaryaee et al. (2018).	Hospital	F, M	adoption of religious/spiritual practices seeking help.  Belief in divine power, adoption of religious/spiritual practices seeking	7.PEDS18296 https://doi.org/10.22034/APJ
Iran. Khanjari et al. (2018). Iran.	Hospital	М	help, adoption of positive attitudes.  Positive coping resource, source of stress, negative interference in	CP.2018.19.4.1063 https://doi.org/10.4103/jfmpc
Nafratilova et al. (2018).	Unspecified	F. M		
Indonesia.		1,00	Maintaining hope, belief in divine power, adaptation, acceptance, denial due to R/S, adoption of religious/spiritual practices seeking help, emotional support.	https://doi.org/10.4103/IJPC. JPC_195_17
Walubita et al. (2018). Zambia.	Hospital	Cr	Refusal of treatment due to beliefs, replacement of conventional reatment with faith, social support, adaptation, belief in divine power,	https://doi.org/10.1186/s1291 3-018-3127-5
Behzadi et al. (2018). Iran.	Hospital	M	maintaining hope.	https://www.ncbi.nlm.nih.go
Behzadi et al. (2018). Iran. Moghaddasi et al. (2018). Iran.	Hospital	10 Mars	Coping resource.  Strengthening religious/spiritual beliefs, coping resources, shaken faith,	/pmc/articles/PMC6048007/ https://dei.org/10.1007/s0052
Moghaddasi et al. (2018). Iran. Mazhari et al. (2019). Iran.	37000	HT	questioning faith.	0-018-4289-8
	Hospital	F, M	Sense of gratitude, emotional support, adaptation.	https://doi.org/10.1007/s1094 3-019-00959-8
Paula et al. (2019). Brazil.	Hospital	Cr	Belief in divine power, social support, bond strengthening.	http://dx. do org/10.15649/cuidarte. v10i1
Bozkurt et al. (2019). Turkey.	Hospital	М	Positive effects on wellness.	570. https://doi.org/10.1177%2F1
Tan et al. (2019). Singapore.	Hospital	м	Feeling of gratitude.	043659618818714 https://doi.org/10.1177%2F1
Ahmadi et al. (2019). Iran.	Medical Center	M	Emotional support, adoption of religious/spiritual practices seeking help.	054773819888099 https://doi.org/10.1017/S147/
Rabelais et al. (2019). United	Hospital	Cr. C	stress relief, maintaining hope, relief.	041419000743
States. Lion et al. (2019). United	Hospital	F, Pt	Strengthening R/S, adoption of religious/spiritual practices seeking help, belief in divine power, maintaining hope. Adoption of religious/spiritual practices seeking help, belief in divine	https://doi.org/10.1188/19.0 NF.170-184 https://doi.org/10.1002/pbc.2
States.  Dournit et al. (2019). Lebanon.	Hospitalization	F, M	Autopoint of integration printing practices seeking neigh, desired in drysteller power, maintaining hope.  Emotional support, belief in divine power.	https://doi.org/10.1002/pbc.2 7971 https://doi.org/10.1016/j.ejon
The state of the s	and ambulatory units	*5:01	and appears, course in sevene power.	2018.12.009
	Hospital	F, M	Maintaining hope, belief in divine power, adoption of religious/spiritual	https://doi.org/10.1111/ecc.13 061
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Figure 2. Articles according to authorship, authors' year and country, location, attendees, how R/S were described/used by attendees, and DOI/URL\*.

and spirituality are significant socio-cultural components, as in Latin American and Middle Eastern countries. In societies where R/S is more present, it is expected that such resources

may be more commonly evoked since these dimensions are part of sociability and may materialize in people more systemically and integrally (Rossato et al., 2021). Thus, R/S is necessary to be understood because an individual's belief system and ways of thinking are culturally built and because culture influences social life through institutions, laws, knowledge, customs, and morals that interfere with lifestyles (Ahmadi et al., 2018).

Evidence shows that religion, religiosity, and spirituality are important to most of humanity, with about 85% of the world's population claiming membership in a religious group (Loewenthal, 2019). Thus, regardless of culture, religious and spiritual components will be exerting implications on people's way of life, even those who do not have or follow a belief.

The hospital was the place evidenced as the main field of data collection where the participants were recruited, followed by support homes and other health and family support institutions. This aspect shows the ample structure necessary for the sick people's treatment and for the reception of other demands from the families that accompany them. The use of this space can be understood by the fact that in many situations parents are accompanying their children and spend long periods in health institutions. Cancer treatment requires a series of complex procedures, developed over months or years that demand care in tertiary health centers with a large structure of equipment and personnel. This is because treatments today usually include complex chemotherapy regimens that require hospitalization or outpatient visits and can last from 01 to 02 years, and many children require radiotherapy, surgery, and/or bone marrow transplantation (Long and Marsland, 2011).

Mothers and fathers are commonly the people who most accompany the treatment of children and adolescents with cancer, especially mothers. If we sum the studies that presented mothers and fathers and the studies that presented only mothers, we observe that mothers are the main people responsible for providing care. This aspect has been evidenced by the scientific literature, which has also been showing the implications of this factor in family dynamics and the health of this group (Andrade et al., 2014; Santos et al., 2018; Vieira et al., 2020).

Regarding how R/S guided the experiences of family members and caregivers of children and adolescents with cancer, it was possible to observe that this dimension can exert positive influences on coping with cancer, but it can also act as a negative aspect depending on how subjects subjectively experience it. The scientific literature has been very useful in this sense, producing studies that allow us to have a broad understanding of these components of people's lives.

The use of the R/S as a coping resource can be a significant component in the adoption of more adaptive attitudes and behaviors when facing the potentially stressful context. In this sense, professionals and health institutions should be aware of the religious and spiritual needs of family members and caregivers, because R/S can be a complementary device that, added to other adopted welcoming practices, can significantly contribute to the prevention of psychological illness. Healthcare spaces should consider that R/S is present in people's lives and, even though the biomedical and positivist traditions have contributed over the years to the removal of these vertices in formal medical assistance (Rossato et al., 2021), these dimensions are still significant components in the experiences of many subjects.

Many times, cancer in children and adolescents leads family members and caregivers to search for explanations and ways to try to understand the reasons for the illness. In this process of

attributing senses and meanings, sometimes R/S ends up being the vehicle used for the search for answers and can become both a welcoming resource and a negative element, depending on how the subjects understand and use it.

The way family members and caregivers interpret the diagnosis of cancer may be linked to cultural understandings and beliefs of the disease, health, wellness, and death, and spiritual and religious beliefs appear in this context influencing how parents and family members view their children's disease and cope with the situation (Vitorino et al., 2018). Thus, it is observed that in the search for finding a meaning for their children's illness, some family members/caregivers may succeed finding it in religion/spirituality, while others struggle to give meaning to the diagnosis (Schaefer et al., 2020).

The analysis of the articles found in this review showed that the R/S is a coping strategy for parents, helping them to maintain hope that their children will get better and be cured of cancer. In this process, they seek divine intercession through requests, prayers, established conversations, and believe that the will of God/ Allah (or another religious/spiritual figure related to their beliefs) will prevail and determine the destiny of the child/adolescent. The articles found showed that family members/caregivers look to their religious and spiritual beliefs for an additional resource to assist and give hope that all will be well, creating a sense of trust (e.g., Faria and Cardoso, 2010; Nafratilova et al., 2018; Sánchez, 2020). Thus, illness can be seen by family members and caregivers as serving a purpose, whereby God (or another religious/spiritual figure) would be present and accompanying them in the situation they are experiencing, and may generate a sense of comfort and peace (e.g., Cutillo et al., 2018; Chen et al., 2020; Schaefer et al., 2020). To have something to help them reduce anxieties, expectations, fears, and discomforts, the treatment journey needs to be seen in a lighter and more adjusted way in the face of the demands that may emerge (Rossato et al., 2021).

As could be observed in the studies, the emotional/psychological support provided by R/S to deal with anxiogenic and potentially stressful situations proves to be a positive component that helps in maintaining mental health. The attachment to faith and the belief that the children's/adolescents health can improve become a complementary resource to treatment. Thus, one seeks something that goes beyond the traditional methods of treatment available in the health services, and these strategies give sustenance, support, and strength to the subjects during the journey (e.g., Faria and Cardoso, 2010; Almico and Faro, 2014; Paula et al., 2019). Thus, health professionals are not responsible for judging whether these behaviors that were adopted by family members and caregivers are right or wrong, but rather to monitor how these individuals will experience this process, to guide and support them along the way while respecting their beliefs.

The religious and spiritual aspects of family members and caregivers were also strengthened during children and adolescents' illness. The results showed the adoption of religious and spiritual practices as a way to get closer to God, with an openness to the use of objects and participation in rites/practices directed to R/S, such as going to certain places considered sacred (e.g., Wang et al., 2017; Ahmadi et al., 2019; Rabelais et al., 2019; Chen et al., 2020). Going to sacred places or adopting certain habits and objects linked to personal religiosity/spirituality are ways of establishing a connection and contact with a superior force that transcends concrete/material existence, and these actions are positive for people (Rossato et al., 2021).

It is important to consider the elements described in the studies to guide the work focused on the welcoming of religious and spiritual practices in health institutions. Many times, because they stay for long periods following the treatment, family members and caregivers do not have their needs met nor a place where they can profess their beliefs. Thus, what we see is that not always the beliefs of the sick people and their wishes regarding religious and spiritual practices are respected or even considered in the therapeutic itinerary (Rossato et al., 2021). The data found are significant subsidies that also demonstrate the importance of attention to religious and spiritual dimensions by health professionals and especially by chaplaincy services in institutions.

It is evident that nowadays there is a need for chaplains to be incorporated into healthcare practices, as they contribute significantly to the care that is offered, as shown by the scientific literature (Carey et al., 2018; Nash et al., 2018; Lion et al., 2019; Proserpio et al., 2019). These professionals help patients and families to face spiritual suffering, they make communication between the family and the health team much easier, and they provide support for religious and spiritual practices in health institutions (Rossato et al., 2021), among other aspects that demonstrate the relevance of their insertion in multidisciplinary teams that care for children and adolescents with cancer. In this context, it is important that these professionals receive adequate training to acquire the necessary skills to provide religious and spiritual care, an aspect that has already been required (Fitchett et al., 2015; Cadge et al., 2019, 2020).

Other aspects that need to be highlighted concerning the use of R/S by family members and caregivers evidenced in the results and that cannot be disregarded refer to the negative aspects of this dimension in the subjects' lives. Among the studies that were found, the questioning of faith was one of the most recurrent elements in the participants' speeches. This questioning of faith was expressed through questioning concerning the motivations that could have led to the appearance of cancer, attitudes that they would have had and that displeased God and therefore were punished (e.g., Banerjee et al., 2011), as if the disease was a test for faith (e.g., Arabiat et al., 2013), or a divine punishment (e.g., Reisi-Dehkordi et al., 2014; Nikfarid et al., 2017), among other aspects

In other situations, it was observed that parents' beliefs varied according to the improvement or worsening of their children's health conditions (Kudubes et al., 2014). They also questioned the existence of God and felt abandoned by Him (e.g., Freitas et al., 2017; Nicholas et al., 2017). When experienced negatively by family members and caregivers, R/S can enhance psychopathological symptoms, contributing, for example, to the emergence of symptoms of stress, anxiety, anguish, and depression, which interfere with the quality of life (e.g., Khanjari et al., 2018; Vitorino et al., 2018).

In another context, the conventional and scientifically proven treatment for cancer was replaced by other methods due to aspects linked to family members' beliefs (e.g., Walubita et al., 2018). In that same article, the authors describe that religious and spiritual leaders also influenced parents by discouraging them from seeking medical help for the children'/adolescents treatment with cancer and saying that the sick person had been cured of the disease.

The data that was found in the articles highlighting the negative aspects of R/S are important to be considered and an indication that healthcare professionals and chaplains must be aware of them. Negative religious coping can lead to poorly adaptive

coping strategies that increase psychological distress (Dolan et al., 2021) and, consequently, interfere with the quality of life and the occurrence of psychopathological symptoms.

Particularly, vulnerable parents may experience increased anxiety that stems from their feelings of being punished by God or the divine (Dolan et al., 2021). In this way, this negative religious/spiritual coping represents struggles in the person's relationship with God and/or religious community and includes strategies such as the reassessment of the punishing God (McGrady et al., 2021). Consequently, these existing conflicts weaken the subjects' relationships with their faith, with God, and with their religious and spiritual group, they belong to/were part of with negative repercussions on the quality of life.

## **Final considerations**

The use of R/S during childhood cancer treatment was pointed out as a coping strategy by family members and caregivers. In the last decade literature, there has been a predominance of references that show that R/S is a resource that acts positively in coping with illness, bringing an active spiritual/religious life, emotional support, strengthening of ties with divine figures, maintenance of hope, and resilience, among other aspects. This evidence reinforces the consideration of R/S as an apex in health care.

However, in another small portion of the studies that were retrieved, it was possible to evidence faith being expressed in a questioning way, with the parents, and caregivers no longer being a positive resource and becoming one more factor of incomprehension and blame for the children'/adolescents' illness, especially considering the repercussions on the fathers, mothers, and caregivers. Thus, in these studies, R/S did not work as a source of support, but as an element promoting more suffering and not contributing to the treatment and all the necessary care with the sick children and adolescents. Although both movements — both positive and negative experiences regarding R/S — have been already described in the literature before this review, it is noted that R/S association with negative outcomes is still poorly analyzed.

Among the limitations of this study, we highlight the time frame that did not allow us to compare the productions carried out after the Pandemic of the new Coronavirus (COVID-19), which may have brought repercussions to the context of oncologic care and also to the reflections around R/S. These shreds of evidence that have been produced from 2020/2021 onwards are expected to be embodied in the coming years, even allowing us to understand whether or not there have been modifications regarding the phenomenon investigated in this study due to this global context. Another limitation was the language considered in the publications. Articles in English, Portuguese, and Spanish were included in the sample and, therefore, studies in other languages may not have been considered. Monitoring these productions in the short and medium term may also be essential for maturation concerning the phenomena prioritized here.

In terms of potentialities, this study contributes to continuing studying R/S considering the different outcomes that this dimension can have on the subjects, especially in situations of intense emotional mobilization, as in the case of cancer that affects children and adolescents. Because of new studies, it is necessary to access in a more particular way the contexts that these negative answers have produced concerning R/S, understanding if this is due to the type of illness, to the clinical conditions of the sick person, to the religious belonging manifested by parents and

caregivers, to the support networks centered on elements of religiosity and spirituality, among other variables that could explain the use of R/S or its outright refusal in these itineraries. These processes can be better addressed in future studies, contributing not only to the construction of evidence, but also to a better deepening in elements that cannot be taken exclusively as dichotomous, for example, either R/S contributes or R/S does not contribute, but rather the nuances of this evaluation.

Reviewing these studies and producing new evidence based on the existence of different possibilities of reading the phenomenon of R/S in health care can bring us closer to a more realistic understanding of this vertex and, in this way, critically embody this dimension in health care and, specifically, in Pediatric Oncology, the focus of this research. In a scenario that has been increasingly open to the incorporation of R/S in the healthcare contexts, it is of utmost importance that such processes be based both on reliable evidence and on an attitude of respect for integral care, represented here by this vertex.

**Acknowledgments.** To Coordination for the Improvement of Higher Education Personnel (CAPES) and The Nacional Council for Scientific and Technological Development (CNPq), Ministry of Education of Brazil. To University of São Paulo and to University of Salamanca, for institutional support.

**Funding.** This study was financed by the Coordination for the Improvement of Higher Education Personnel (CAPES) and by the National Council for Scientific and Technological Development (CNPq), Ministry of Education of Brazil.

**Conflict of interest.** The first author has received research grants from Coordination for the Improvement of Higher Education Personnel (CAPES). Organization linked to the Ministry of Education of Brazil. The fourth author has financial support from the Nacional Council for Scientific and Technological Development (CNPq). According to ethical standards, this manuscript has no other conflict of interest.

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