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Spirituality in children with complex chronic conditions and their caregivers

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Abstract

This study investigated how children and adolescents with complex chronic conditions under palliative care and their families experience spirituality. To this end, an integrative literature review was conducted, with searches in the PubMed, Web of Science, and Scopus databases between August and September 2024. Fourteen articles that corresponded to the scope of this study were selected and most were qualitative. Thematic categorical analysis identified three categories: patients' spiritual perceptions and needs; factors influencing the experience of spirituality, such as age, diagnosis, and family context; and spirituality as a coping strategy for family members to promote emotional well-being. The results indicate that spirituality is fundamental to comprehensive care, as it promotes resilience and adaptation to illness. This dimension is influenced by multiple factors and constitutes an essential resource for coping with emotional and existential challenges. Its systematic inclusion in pediatric palliative care is recommended to improve the well-being of patients and family members.

Keywords: Spirituality. Chronic disease. Palliative care. Child. Adolescent. Family.

Resumo

Espiritualidade em crianças com condições crônicas complexas e seus cuidadores

Este estudo investigou como crianças e adolescentes com condições crônicas complexas em cuidados paliativos e suas famílias vivenciam a espiritualidade. Para isso, realizou-se revisão integrativa da literatura, com buscas nas bases PubMed, Web of Science e Scopus entre os meses de agosto e setembro de 2024. Foram selecionados 14 artigos, majoritariamente qualitativos, que correspondiam ao escopo do estudo. A análise categorial temática identificou três categorias: percepções e necessidades espirituais dos pacientes; fatores influenciadores na vivência da espiritualidade, como idade, diagnóstico e contexto familiar; e espiritualidade como estratégia de enfrentamento dos familiares para promover bem-estar emocional. Os resultados indicam que a espiritualidade é fundamental no cuidado integral, pois favorece resiliência e adaptação ao adoecimento. Essa dimensão é influenciada por múltiplos fatores e constitui recurso essencial para enfrentar desafios emocionais e existenciais. Recomenda-se sua inclusão sistemática no cuidado paliativo pediátrico para melhorar o bem-estar de pacientes e familiares.

Palavras-chave: Espiritualidade. Doença crônica. Cuidados paliativos. Criança. Adolescente. Família.

Resumen

Espiritualidad en niños con enfermedades crónicas complejas y sus cuidadores

Este ensayo investigó cómo los niños y adolescentes con enfermedades crónicas complejas en cuidados paliativos y sus familias experimentan la espiritualidad. Com este fin, se realizó una revisión integradora de la literatura, con búsquedas en las bases PubMed, Web of Science y Scopus entre los meses de agosto y septiembre de 2024. Se seleccionaron 14 artículos, en su mayoría cualitativos, que se ajustaban al alcance del estudio. El análisis temático categórico identificó tres categorías: percepciones y necesidades espirituales de los pacientes; factores que influyen en la experiencia de la espiritualidad, como la edad, el diagnóstico y el contexto familiar; y la espiritualidad como estrategia de afrontamiento de los familiares para promover el bienestar emocional. Los resultados indican que la espiritualidad es fundamental en la atención integral, porque favorece la resiliencia y la adaptación a la enfermedad. Esta dimensión está influenciada por múltiples factores y constituye un recurso esencial para afrontar los retos emocionales y existenciales. Se recomienda su inclusión sistemática en los cuidados paliativos pediátricos para mejorar el bienestar de los pacientes y sus familiares.

Palabras clave: Espiritualidad. Enfermedad crónica. Cuidados paliativos. Niño. Adolescente. Familia.

Research

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In recent decades, Brazil has undergone economic, cultural, demographic and environmental transformations that have significantly impacted child health. There have been notable advances, such as the reduction in infant mortality, which declined from 26 to 15 deaths per 1,000 live births between 2000 and 2022, as well as increases in vaccination coverage and breastfeeding rates[1]. However, challenges persist, including a rise in childhood obesity, whose prevalence among children aged 5 to 10 increased from 11.1% to 13.8% in boys and from 9.1% to 11.2% in girls[2]. An increase in the incidence of noncommunicable diseases among children has also been observed, reflecting changes in health and lifestyle patterns[3]. In addition, the rate of preterm births remains high, with 11.1% of births between 2011 and 2021 occurring before the 37th week of gestation[4].

These factors directly contribute to the growing number of children with complex chronic conditions (CCC), a group characterized by continuous and multi-layered care demands that include not only clinical issues but also psychosocial and long-term needs[5]. The increase in prematurity, noncommunicable diseases and lifestyle-related conditions highlights a shift in the pediatric epidemiological profile, with significant implications for health systems and pediatric care practices[6].

In recent decades, the growth of the pediatric population with CCC has underscored the need for a comprehensive approach to healthcare. These conditions require not only specialized clinical interventions but also attention to the social vulnerabilities surrounding these children and their families, which directly affect family routines and functioning, sociability, and the participation of the child or adolescent, in addition to social and emotional vulnerabilities[7,8].

In this context, the need to provide people-centered, comprehensive care and to ensure quality of life for patients diagnosed with severe, life-threatening illnesses with no prospect of cure gave rise to the specialty known as palliative care (PC).

According to the World Health Organization (WHO), palliative care is an approach aimed at preventing and alleviating the suffering of patients diagnosed with life-threatening illnesses[9]. D'Alessandro and collaborators[10] emphasize the importance of promoting quality of life throughout the illness process, which does not necessarily imply that the patient is in the terminal phase of life; rather, it underscores the need for holistic care to ensure relief from suffering and the preservation of human dignity.

In this regard, it is important to highlight the concept of total pain, which emerged from the professional experiences of Cicely Saunders, one of the pioneers of palliative care development in Europe[11]. This concept acknowledges the multiple dimensions of the pain experience and recognizes that comprehensive care must include the various characteristics inherent to human life. Through her work, Saunders identified physical, emotional, social and spiritual dimensions associated with the experience of pain, which therefore transcends purely physical sensations[11].

Spirituality can be understood in various ways and may include religious beliefs, the search for meaning, connection with something greater or meditation practices. It has the potential to offer emotional support and comfort during challenging periods[12]. In line with its comprehensive view of the human being, palliative care recognizes the importance of spirituality and promotes a holistic approach to patient care that takes into account spiritual, cultural and religious needs[13].

Regarding the process of childhood illness, Jackson[14] emphasizes that children possess a profound spiritual life, which becomes particularly evident in moments of crisis such as illness and loss, and that this dimension can serve as an important emotional and existential resource. Recognizing and integrating this spirituality into care can be essential for promoting comfort and meaning in contexts of suffering.

It is also noteworthy that, based on the theory of Jean Piaget, children understand death according to their level of cognitive development, and this understanding directly influences how they relate to the illness process. In Brazil, one of the earliest studies addressing this topic was conducted by Torres[15], who found that up to the age of two, children do not comprehend the irreversibility of death; between the ages of three and four, they tend to perceive it as a temporary event; between five and seven, they begin to understand its irreversibility, although magical thinking persists; between seven and eleven, they recognize the biological aspects of death; and only from the age of twelve do they fully understand death as universal and definitive.

Complementing this perspective, Alencar and collaborators[16] demonstrate that hospitalized children not only experience death according to their cognitive stage but also articulate subjective understandings influenced by emotional, spiritual and sociocultural factors, particularly in contexts of suffering and prolonged hospitalization. This reinforces the importance of palliative care transcending physical and medical needs and integrating approaches that respect and embrace the spirituality of children and adolescents with complex chronic conditions, as well as that of their families.

Therefore, by understanding the multiple ways in which children and adolescents perceive and cope with death and suffering, healthcare professionals can offer more sensitive and person-centered interventions, promoting improved quality of life and spiritual care throughout the illness process, as well as a dignified and peaceful death for patients, with adequate support for their families[17].

This study aimed, through an integrative literature review, to better understand how spirituality is experienced by children and adolescents with CCC receiving palliative care, as well as by their families, to support the provision of appropriate care and interventions that facilitate this process and promote quality of life until its final stage.

Method

This qualitative study was conducted through an integrative literature review. As noted by Sousa, Bezerra and Egypto[18], this method aims to broadly explore significant studies published on a given subject and to synthesize their multiple findings. To ensure scientific methodological rigor, the following steps were undertaken: 1) formulation of the research question; 2) definition of the literature search strategy; 3) identification and selection of studies from information sources; 4) organization and representation of study characteristics and data; 5) analysis and discussion of results; and 6) synthesis of knowledge and presentation of the review.

To formulate the research question, the research problem was structured using the PCC strategy, a mnemonic in which P corresponds to population (the population under study), the first C to concept (the research concept), and the second C to context (the setting in which the study is conducted)[19]. Accordingly, the guiding research question was: *How do children and adolescents with complex chronic conditions and their families experience spirituality during pediatric palliative care?*

The search process was conducted between August and September 2024 in the PubMed, Web of Science and Scopus databases, selected for their relevance to the health field and for indexing international studies pertinent to the research subject. Initially, free-text searches were carried out to identify studies related to the subject. Subsequently, standardized descriptors from the controlled vocabularies DeCS and MeSH[19] were employed.

The search strategy was developed based on the PCC mnemonic and employed the Boolean operators "and" and "or," according to the following equation: "(parents *or* caregivers or family) *and* (children *or* pediatrics *or* pediatric patients) *and* (chronic illness *or* chronic disease *or* complex chronic conditions) *and* (spirituality *or* meaning-making *or* religious beliefs) *and* (palliative care *or* end-of-life care *or* terminal care)." The use of these operators broadened the scope of the searches and enabled the identification of studies that were more precise and aligned with the subject of investigation.

Inclusion criteria were then established: empirical articles addressing children with complex chronic conditions receiving pediatric palliative care, as well as their family members (parents, siblings and caregivers), with a focus on the meanings attributed to spirituality and religious practices in this context, based on their lived experiences. The studies also needed to be conducted in pediatric palliative care settings, such as hospitals or home-based care.

Publications that had not undergone peer review—such as letters to the editor, studies conducted in organizational contexts, books, book chapters, reviews, commentaries, viewpoints and editorials—were excluded. No restrictions were imposed regarding language or year of publication, provided that the studies met the previously established inclusion criteria.

The selection process was supported by technological tools, including Mendeley, used for organizing and annotating scientific articles, and the Connected Papers platform, which enabled the identification of connections between publications and the expansion of the search for relevant studies.

A structured spreadsheet was used as a data extraction instrument, with the aim of organizing and systematizing the information. The spreadsheet was developed based on the PCC strategy and organized into four categories: 1) study characteristics, including reference, study type, language and objective; 2) population, considering participants, age group and clinical condition; (3) concept, including the main findings and recommendations; and (4) context, specifying the country in which the study was conducted.

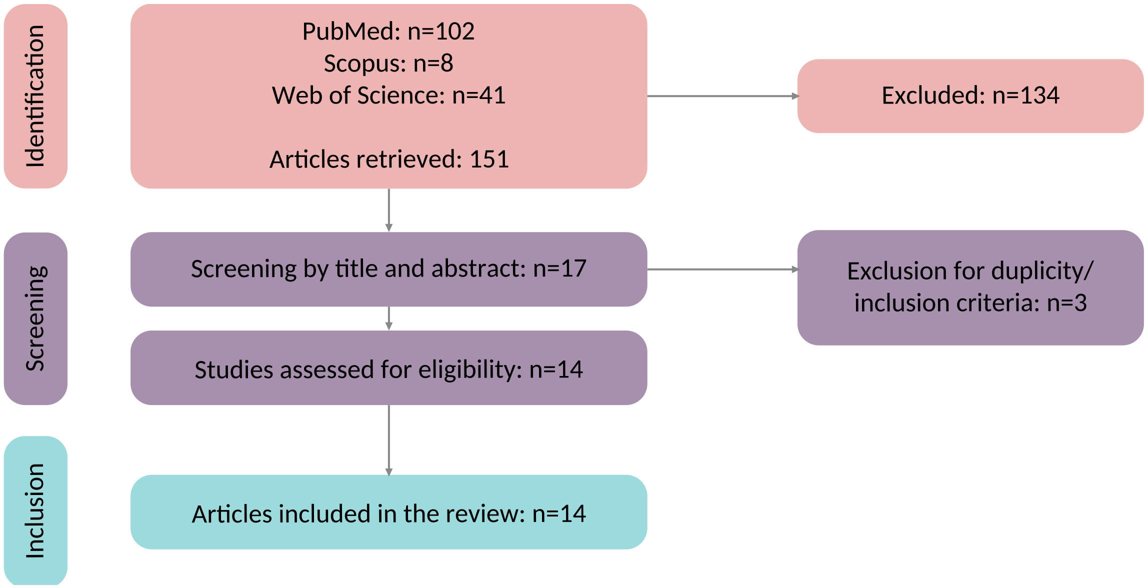
A thematic categorical content analysis was performed in accordance with the framework proposed by Bardin,[20] structured in three stages: pre-analysis, material exploration and treatment of results. This process was supported by NVivo qualitative data analysis software, which assisted in data categorization and interpretation.

Illustrative resources—a flowchart and a summary table—were created to organize and present the results in a clear and accessible manner. In addition, three thematic categories were established, highlighting the most recurrent aspects in each analytical discussion pillar: 1) spiritual needs of children and adolescents with CCC; 2) spiritual experiences in the context of CCC: associated factors; and 3) spirituality as a family coping strategy.

Results

This review comprised 14 original empirical studies published between 2004 and 2024. Using the previously described search equation, a total of 151 articles were identified, of which 102 were retrieved from PubMed, 8 from Scopus and 41 from Web of Science. After applying the eligibility criteria, 14 studies were selected for inclusion in this integrative review, as shown in Figure 1, which presents the flowchart of the stages of identification, screening, eligibility and inclusion of the analyzed articles.

Figure 1. Search and selection of studies



Among the 14 studies selected for this review, seven (50%) were conducted with children and adolescents aged 7 to 21 diagnosed with complex chronic conditions and receiving palliative care, totaling 372 participants. The remaining seven studies (50%) involved family members and caregivers of children with CCC in pediatric palliative care and included 436 participants.

Different data collection instruments were used across the studies, reflecting the complexity of spirituality in pediatric and family health contexts. Qualitative interviews predominated, being used in nine studies (64%)[21-29], including both semi-structured and structured formats. These methods enabled an in-depth exploration of the subjective experiences of children, adolescents, family members and professionals, while capturing nuances related to spiritual beliefs, emotions and individual needs.

Four studies (29%)[30-33] used structured questionnaires or standardized scales, such as the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT-Sp) and the Spiritual Needs Inventory for Patients and Caregivers (SpIRIT). These instruments provided quantitative measures of spiritual and emotional dimensions, facilitating comparison, statistical analysis and the objective mapping of specific aspects of spirituality and religion.

Only one study (7%)[34] employed participant observation to understand the lived experience of participants. This plurality of instruments highlights the authors' concern with capturing both rich subjective data and measurable outcomes, thereby promoting an integrative and contextualized approach to spirituality in healthcare, particularly in situations involving chronic illness and palliative care.

Of the 14 articles analyzed, 10 studies were conducted in the United States of America (71%), two in Brazil (14%), one in the Netherlands (7%) and one in Spain (7%). These data highlight the concentration of scientific production on this subject in the United States.

Chart 1. Synthesis of data extracted from the selected studies

Author; year	Country	Title	Objectives and main findings
Knapp and collaborators; 2011[21]	USA	"Spirituality of parents of children in palliative care"	The study investigated parents' spirituality and its associated factors. It found higher levels of religiosity among non-White parents and reinforced the need to incorporate spiritual assessment into palliative care.
Hexem and collaborators; 2011[22]	USA	"How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times"	The study analyzed how parents use faith during their children's illness. Parents reported support, comfort and moral guidance, but also doubt, anger and distancing from religious practices.
Lyon and collaborators; 2014[23]	USA	"A longitudinal, randomized, controlled trial of advance care planning for teens with cancer: anxiety, depression, quality of life, advance directives, spirituality"	The study tested the feasibility, acceptability and safety of a pediatric advance care planning intervention—family-centered advance care planning for adolescents with cancer.
Alvarenga and collaborators; 2021[24]	Brazil	"Spiritual needs of Brazilian children and adolescents with chronic illnesses: a thematic analysis"	The study investigated how the spiritual needs of children and adolescents with chronic illnesses are addressed during hospitalization. It found that these needs are essential for meaning-making and hope, yet remain insufficiently considered in clinical practice.

continues...

Chart 1. Continuation

Author; year	Country	Title	Objectives and main findings
Alvarenga and collaborators; 2021[25]	USA	"How to talk to children and adolescents with cancer about spirituality? Establishing a conversation model"	The study developed and tested a model to address spirituality with children and adolescents with cancer. The tool showed potential to enhance the quality of spiritual care and to foster qualitative research in the field.
Livingston and collaborators; 2020[26]	USA	"Shared spiritual beliefs between adolescents with cancer and their families"	The study analyzed the alignment between the beliefs of adolescents and their caregivers. It observed that beliefs are not always aligned and that many caregivers underestimate the importance of spirituality for adolescents.
Superdock and collaborators; 2018[27]	USA	"Exploring the vagueness of religion & spirituality in complex pediatric decision-making: a qualitative study"	The study explored how parents use religion and spirituality in clinical decision-making. Spirituality influences the way decisions are made, even when vaguely expressed, and may have functional or dysfunctional effects.
Brouwer and collaborators; 2023[28]	Netherlands	"Barriers to the spiritual care of parents taking care of their child with a life-limiting condition at home"	The study explored, from the perspectives of bereaved parents, chaplains, grief counselors and primary healthcare providers, the barriers to supporting parents' spiritual needs.
Alvarenga and collaborators; 2024[29]	Brazil	"'God gives me hope!': Hospitalized children's perception of the influence of religion in coping with chronic illness"	The study recognized the role of religion in helping hospitalized children cope with chronic illness. It identified faith as a source of strength, emotional support and meaning in the experience of illness.
Arutyunyan and collaborators; 2016[30]	USA	"Religion and spiritual care in pediatric intensive care unit: parental attitudes regarding physician spiritual and religious inquiry"	The study analyzed parental attitudes toward discussing beliefs with physicians. Parents showed ambivalence, suggesting that chaplains may sensitively mediate this communication.
Kelly, May, Maurer; 2016[31]	USA	"Assessment of the spiritual needs of primary caregivers of children with life-limiting illnesses is valuable yet inconsistently performed in the hospital"	The study assessed caregivers' perceptions of how their spiritual needs are addressed in the hospital setting. It indicated that such needs are undervalued, despite being essential to feelings of support.
Grossoehme and collaborators; 2020[32]	USA	"Association of religious and spiritual factors with patient-reported outcomes of anxiety, depressive symptoms, fatigue, and pain interference among adolescents and young adults with cancer"	The study investigated associations between spirituality and symptoms such as anxiety and fatigue. It demonstrated that a sense of meaning and peace acts as a positive mediator, with potential implications for palliative interventions.
Miquel, Clemente, Ciccorossi; 2024[33]	Spain	"Exploring spirituality, religion and life philosophy among parents of children receiving palliative care: a qualitative study"	The study explored parents' spirituality, religiosity and philosophy of life in coping with the care of children with palliative care needs. It proposes an individualized approach, sensitive to parental uniqueness.
Bull, Gillies; 2007[34]	USA	"Spiritual needs of children with complex healthcare needs in hospital"	The study investigated hospitalized children's perspectives on spiritual care. It emphasized that recognizing and addressing children's spirituality is part of clinical responsibility.

Discussion

Spiritual needs in children and adolescents

According to the selected studies, the experience of spirituality is not limited to specific religious practices but also related to something broader—a connection with something greater—and is associated with positive outcomes in coping with chronic illness. The literature indicates that children and adolescents, whether religious or not, have spiritual needs that include connections with significant others, i.e., healthy relationships with themselves, with others, with the world and with a transcendent dimension.

In the study by Alvarenga and collaborators [24], five types of spiritual needs were identified: 1) the need to find meaning in illness and a sense of purpose in life; 2) the need to sustain hope; 3) the need to express faith and engage in religious practices; 4) the need for comfort at the end of life; and 5) the need to connect with friends and family members.

Regarding the need to remain connected with friends and family, Bull and Gillies [34] report that, in all five interviews conducted in their study, relationships with friends, family members and even healthcare professionals were mentioned as important for fostering feelings of safety and comfort. According to the authors, none of the children referred to a religious community or to God until specifically asked about these aspects, reinforcing the notion that childhood spirituality is not reduced to religion.

Similarly, Alvarenga and collaborators [25], in a study conducted in Brazil, highlight the importance of relationships in the experience of spirituality, including connections with the sacred and with deceased relatives. From this perspective, the quality of care and closeness to significant people are understood as fundamental elements of the spiritual care of children and adolescents.

Regarding the need to express faith and engage in religious practices, Alvarenga and collaborators [29] report that some participants expressed the desire and need to attend church, read the Bible, wear religious symbols and even receive visits from religious leaders during hospitalization. These findings make it possible to observe the role of the religious community in spiritual care.

However, it is noteworthy that in the study by Alvarenga and collaborators [25], there was ambivalence regarding whether healthcare professionals should initiate discussions about spirituality. Some patients reported that they themselves should begin the conversation, while others believed that the initiative should come from the healthcare professional. In this regard, Bull and Gillies [34] argue that recognizing children's spiritual needs—whether or not they involve religious beliefs and practices—is a responsibility of healthcare professionals, which includes identifying and addressing these needs as part of care.

It is also worth noting that, concerning the need to maintain hope, the studies identified spirituality as a favorable factor for the well-being of children and adolescents. According to Alvarenga and collaborators [29], hope promotes acceptance of illness and adherence to treatment, and may contribute to greater life satisfaction.

With respect to emotions, Lyon and collaborators [23] emphasize that participation in an advance care planning program significantly reduced anxiety among adolescents. In turn, Livingston and collaborators [26] underscore the importance of early identification and the provision of continuous spiritual care for patients for whom religion and/or spirituality are meaningful, given that this dimension is not relevant for all individuals [32].

It is also evident that the need to maintain hope is closely related to the need for connection with significant others, since, as noted by Alvarenga and collaborators [24], interpersonal relationships with family members and the healthcare team were able to reduce feelings of hopelessness.

Regarding the need to find meaning in illness and a sense of purpose in life, Alvarenga and collaborators [29] report that children and adolescents demonstrated spiritual care needs not only to sustain hope for healing but also to receive support throughout the illness process and in the search for relief from suffering. According to the authors, viewing illness as part of God's plan or a higher purpose fosters in children and adolescents a sense of trust in a superior being who is in control and caring for them and their families. They also perceive the illness process as an opportunity for growth and learning, which promotes psychological and emotional well-being.

With regard to the need for comfort at the end of life, Alvarenga and collaborators [24] report that children and adolescents wish to maintain a good quality of life and want their family members to be supported by the healthcare team at the time of death. They also express fantasies about what this moment will be like. No findings were identified in the other studies that differed from the well-being generated by holistic and individualized care.

Spiritual experiences: associated factors

According to the literature selected for this review, patients' spirituality is shaped by several factors, such as age, diagnosis, family background and personal experience with illness. Religion and family—particularly parents—have a significant impact on the formation of spirituality in children and adolescents with complex chronic conditions.

Most participants in the study by Alvarenga and collaborators [29] practiced a religion that was the same as their parents'. Bull and Gillies [34] also describe parents as playing a key role in the lives of children and adolescents, exerting a profound influence even on their sense of fulfillment, which is shaped by their parents' perceptions of them.

However, it is noteworthy that, according to Livingston and collaborators [26] family members feel more connected to a higher being than adolescents. Young people reported feeling less strengthened in their faith in the face of a cancer diagnosis when compared with their families. Alvarenga and collaborators [29] note that although Fowler's theory of faith development—according to which faith evolves throughout life in different stages, in a manner similar to cognitive and moral development—posits a relationship between age and faith development, no satisfactory correlation between these variables was identified. It was also observed that the spirituality of children and adolescents may be influenced by the illness process itself.

In this context, Alvarenga and collaborators [29] report an intensified search for a higher power, including engagement in religious practices such as attending church. In other words, although participants already practiced a religion and believed in God prior to diagnosis, a more intimate relationship developed after the onset of illness. However, the same study also identified negative aspects related to religious practices, as some children reported feelings of regret for not having sought this closeness earlier, including through church attendance [29].

In this regard, Bull and Gillies [34] argue that the level of help attributed to God is proportional to the child's health condition and the need for hospitalization. In other words, children's views of God are not abstract or theological; when they speak of God, their perceptions are simple, concrete and linked to the immediate experience of illness and hospitalization. They estimate how much God can help according to the severity of the situation they are facing.

Hence, as argued by Alvarenga and collaborators [25], from the moment of a difficult diagnosis—whether involving invasive treatments or not—through to the end of life, spiritual care is important and meaningful. Healthcare professionals should view children's spirituality as broader than religious faith alone, including comfort, relationships and reassurance.

Spirituality as a family coping strategy

Spirituality can also influence how parents and/or caregivers of children and adolescents experience the illness process. More than 85% of the caregivers interviewed by Kelly, May and Maurer [31] considered faith and spirituality important, and more than 80% of participants in the study by Arutyunyan and collaborators [30] reported being religious and/or spiritual.

Thus, spirituality stands out as a powerful factor in promoting well-being. According to Hexem and collaborators [22], religious practices such as prayer and Bible reading foster a sense of tranquility, calm and peace. As noted by Miquel, Clemente and Ciccorossi[33], prayer is understood by parents as an integral part of the child's care, in addition to promoting human and community connections. The study by Knapp and collaborators[21] reinforces this understanding, as most participants reported having found peace and meaning.

More than 75% of the participants in Arutyunyan and collaborators[30] stated that prayer and meditation were part of their routine. According to Superdock and collaborators[27+] family members trusted that their prayers made a difference in their children's clinical condition. However, the authors also reported that while some parents prayed incessantly, others described experiences of prayer exhaustion and fatigue.

Miquel, Clemente and Ciccorossi[33] report that some parents experienced a significant strengthening of their beliefs following their children's diagnosis, which helped them accept the situation. Even those who stated that they did not follow a specific religion reported connections related to non-religious spirituality.

According to the same authors[33], spirituality provides support and hope during difficult times and thus encourages resilience in the face of their children's illness. One participant stated that they perceived the illness as a test, a trial of their capacity to fight[33].

For Brouwer and collaborators[28], the lack of acknowledgment of parents' distress in the face of challenges may generate or intensify feelings of loneliness and exhaustion. According to Superdock and collaborators[27], feelings of anger and frustration were identified among parents in response to unanswered prayers; however, after the child's death, no parent reported the persistence of these feelings. Hexem and collaborators[22] add that many parents reported questioning their faith during their children's illness and withdrew from their specific religious communities. They also highlighted emotional fluctuation, meaning that even parents who sought to maintain their faith experienced ambivalent feelings.

Parents' belief that God is overseeing their children's care promotes a sense of hope for healing, and the conviction that everything that happens, regardless of the outcome, is under God's control enables them to find meaning even in suffering. Thus, according to Hexem and collaborators[22], parents ground their medical decisions regarding their children—such as choosing the hospital and accepting or refusing treatment, including medical procedures—in their beliefs, which in turn provides them with confidence and reassurance in these decisions. Arutyunyan and collaborators[30] report that nearly half of the participants in their study stated that their spirituality or religious belief influences decisions about their children's medical care. However, according to Superdock and collaborators[27], parents' choices related to clinical processes may lead to disagreements with the healthcare team.

Beyond specific religious practices, Miquel, Clemente and Ciccorossi[33] emphasize the importance of interpersonal relationships in caring for the spirituality of family members and caregivers of children and adolescents with CCC. This network of relationships includes the healthcare team, the patient, friends and family members; nevertheless, parents may feel isolated as the illness process requires adaptations in family roles. Superdock and collaborators[27] argue that support networks are a significant factor in spirituality and religiosity and underscore the importance of friends, community and religious leaders.

Final considerations

From the analysis of the selected studies, it was observed that the spirituality of children and adolescents with complex chronic conditions, as well as that of their families, transcends religious practice and is understood as a broad and multi-layered dimension of connection with oneself, with the world and with a transcendent element. However, it is primarily experienced through connections with significant people and aspects, and these interpersonal relationships include members of the healthcare team.

The spiritual needs identified in children and adolescents include the desire to find meaning in the illness process, sustain hope, express faith and maintain religious practices, receive comfort at the end of life, and preserve emotional bonds with family members, friends and the healthcare team. These needs are, in turn, shaped by individual factors such as age and diagnosis, as well as by family and cultural backgrounds, highlighting the significant influence of parents and support networks on the development and maintenance of spirituality during hospitalization.

Spirituality also emerges as an important coping strategy for caregivers, for whom faith, prayer and interpersonal connections provide emotional support and meaning to deal with the challenges of their children's illness. This spiritual dimension proves essential in promoting well-being, hope, meaning and comfort, especially in contexts of vulnerability and suffering. However, the impact of spirituality may be ambivalent, involving feelings of hope as well as distress, doubt and exhaustion, underscoring the need for sensitive, continuous and individualized spiritual care provided by the healthcare team.

Despite the important role of spiritual care in identifying and addressing spiritual needs, healthcare professionals remain insufficiently prepared to engage with this dimension. As a result, spiritual care is compromised, given the considerable gap in comprehensive care, as some study participants reported that their spirituality was not adequately acknowledged by healthcare professionals. This review demonstrates that spirituality influences decision-making, coping with illness, and emotional well-being. The findings reinforce the importance of integrating spiritual assessment into clinical practice in an ethical manner, respecting autonomy, values and the uniqueness of families, thereby making a relevant contribution to bioethics.

With regard to the authorship of the articles included in this review, most studies were conducted by nurses, revealing the need for greater involvement from other professional groups, since palliative care is delivered by a multiprofessional team committed to comprehensive care. Future research should explore interventions that integrate palliative care, spirituality and bioethical principles, recognizing spirituality as an essential component of health and quality of life for children, adolescents and their families.

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Isabel Regiane Cardoso do Nascimento participated in the study conception, data analysis, and manuscript drafting. Aurilene de Oliveira Lima participated in data search, selection, organization and discussion. Ana Caroline Araujo da Silva partiipated in the discussion of results, and text revision. Hernani Pereira dos Santos contributed in the supervision, critical revision of intellectual content, and final approval of the manuscript. Ilvana Lima Verde Gomes participated in the supervision, critical revision of intellectual content and final approval of the manuscript.

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