



Spirituality in children with life-limiting, life-threatening and/or complex chronic conditions: A scoping review



Mónica Santos Ferreira^{a,c,*}, Diana Gomes Pereira^{a,d}, Sílvia Caldeira^b

^a Universidade Católica Portuguesa, Faculty of Health Sciences and Nursing, Lisbon, Portugal

^b Universidade Católica Portuguesa, Faculty of Health Sciences and Nursing and Center for Interdisciplinary Research in Health, Portugal

^c Hospital de Cascais Dr. José de Almeida, Portugal

^d CUF Cascais, Lisbon, Portugal

ARTICLE INFO

Article history:

Received 25 June 2025

Revised 16 November 2025

Accepted 16 November 2025

Available online xxxxx

Keywords:

Palliative care

Paediatric nursing

Spirituality

ABSTRACT

Purpose: To map available knowledge about spirituality in children with life-limiting, life-threatening and/or complex chronic conditions.

Methods: This review followed the Joanna Briggs Institute methodology for scoping reviews. Registration was done with the Open Science Framework. The searches were conducted in PubMed, CINAHL Complete, Psychology & Behavioral Sciences Collection, via EBSCOhost, and in the Portuguese Open Access Scientific Repository, in September 2024. The sample was composed of 48 studies.

Results: The concept of spirituality is represented by the relationship established with oneself, with the world, and the notion of transcendence. Spiritual needs relate to developmental stage, relationships, sense of normalcy, meaning, and purpose. The relationship established between spirituality and illness is bidirectional, represented by beliefs, practices, and mechanisms of spiritual adaptation. Spiritual care is about supporting children with insights about beliefs, values and behaviours, addressing needs inherent in the developmental process, setting achievable goals that can support a meaningful life and legacy, fostering connections, mediating communication, improving spiritual coping, alleviating spiritual suffering, managing losses, and redefining hope.

Conclusions: This review underlines the complexity, variability, and importance of spirituality while living within a complex, life-threatening or life-limiting paediatric context. However, there is still an urgent need to develop studies on the concept in specific subgroups of this paediatric population.

Clinical implications: Spirituality has an undeniable and aggregating role throughout the course of a life-limiting, life-threatening and/or complex chronic condition. Spiritual care and nurturing should be prioritised in care plans within these complex paediatric contexts.

© 2025 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Introduction

In recent years, advances in scientific and technological knowledge have led to both innovation and increased complexity in healthcare systems (Nasir et al., 2018). This evolution is paralleled by a global rise in complex, life-limiting, and/or life-threatening chronic conditions among children (Chambers, 2018). It is estimated that approximately 21 million children worldwide fall into one of four categories within this clinical domain (Connor et al., 2017). These categories encompass around 400 distinct conditions, including: (1) life-threatening illnesses for which curative treatment may be possible but is not always

successful; (2) conditions where premature death is inevitable; (3) progressive diseases without available curative treatments; and (4) irreversible but non-progressive conditions that result in severe disability (Chambers, 2018). These complex conditions present significant challenges to the development, health, and overall well-being of children and adolescents, necessitating approaches that are tailored to their diverse and evolving needs (Chambers, 2018).

In the course of development, children show a natural ability to integrate the diversity of spiritual experiences they have had, giving them meaning through spirituality, religiosity, or another source with explanatory potential (Coles, 1991; Hay & Nye, 2006). They seek to find meaning and purpose in the experience of illness, to transcend suffering, and to connect with themselves, with others, and/or with something meaningful (Jackson, 2012).

The European Association of Palliative Care defines spirituality as a dynamic and multidimensional dimension of human life, characterized

* Corresponding author at: Universidade Católica Portuguesa, Palma de Cima, 1649-023 Lisboa, Portugal.

E-mail address: s-mopafferreira@ucp.pt (M. Santos Ferreira).

by the experience, expression, and search for meaning, purpose, or transcendence, through the relationship with oneself, with others, with nature, with the symbolic, and/or sacred (Gijbets et al., 2019; Nolan et al., 2011). Spirituality is widely regarded as a complex and multifaceted concept, with meanings that vary significantly across individuals (Timmins & Caldeira, 2017).

In paediatric contexts, this complexity is further heightened by conceptual challenges related to children's developmental stages, age, and personal experiences, all of which play a crucial role in shaping how meaning is attributed, and how spirituality is expressed (Alvarenga et al., 2017; Smith & McSherry, 2004). These challenges are particularly pronounced for children living with complex, life-limiting and/or life-threatening chronic illnesses, whose lived experiences often differ markedly from typical childhood experiences. The literature on spirituality in this population highlights a distinct and often profound journey, marked by frequent and intense encounters with uncertainty, fear, loss of hope, separation from loved ones, and shifts in self-identity (Alvarenga et al., 2017).

The conceptual challenges surrounding spirituality also extend to the practical implementation of care that addresses the spiritual domain. Spiritual care is broadly defined as the support provided to individuals as they seek, construct, and sustain a sense of meaning and purpose in life, particularly in the context of trauma, illness, and other health-related adversities (Timmins & Caldeira, 2017). In paediatric settings, spiritual care has been described as an intervention that helps children and families develop new narratives of meaning and normality in the face of disruption and uncertainty (Davies et al., 2002).

The research question that guided this review was:

- What evidence is available in the literature on the spirituality of children, adolescents and young adults with complex, life-limiting and/or life-threatening chronic illnesses?

In addition, the following secondary questions were examined:

- What are the representations of the concept of spirituality for children with complex, life-limiting and/or life-threatening chronic illnesses?
- What are the spiritual needs and concerns of children with complex, life-limiting and/or life-threatening chronic illnesses?
- What evidence is available on the relationship between spirituality and illnesses?
- What evidence is available in the literature on the field of spiritual care for children with complex, life-limiting and/or life-threatening chronic illnesses?
- What is the thematic evidence that requires future research in the field of spirituality for children with complex, life-limiting and/or life-threatening chronic illnesses?

Material and methods

Protocol and registration

This review followed the Joanna Briggs Institute methodology for scoping reviews (Peters et al., 2024), in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews: checklist and explanation (Tricco et al., 2018). Registration was done with the Open Science Framework in January 2025 (<https://osf.io/tkqaj>).

Eligibility criteria

In the inclusion criteria regarding the concept, population, and context we assume the concept of spirituality in children, adolescents, and young adults (up to the age of 24 years) with complex life-threatening and/or limiting chronic illness, considering the perspectives of the child, adolescent, parents, and healthcare professionals. No contextual

restrictions regarding the place of experience, type of care, or disease stage were applied. Quantitative, qualitative, theoretical or mixed methods studies, published in Portuguese or English, were included, with no time limit. Letters to the editor were excluded.

Information sources and search

The research strategy was developed in three distinct phases (Tricco et al., 2018). The first stage was a preliminary search of existing reviews on the topic in Open Science Framework, PubMed, and the Joanna Briggs Institute for evidence synthesis. It was possible to identify one qualitative metasynthesis, published in 2017, and a scoping review, published in 2023. Both reviews were conducted using methods, criteria, objectives, and/or questions different from those defined for the present review, which justifies the relevance of the present review. A search of the National Library of Medicine (PubMed) and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) was conducted to identify reference articles and provide a brief analysis of the topic. The words found in the titles and abstracts, as well as the indexed terms, were considered in developing the search strategy.

After this analysis, a second stage was carried out in which descriptors (MeSH, CINAHL, specific descriptors for the Psychology & Behavioral Sciences Collection, free terms) and Boolean operators were selected and combined to form the most appropriate search equation for each database and repository, also taking into account the use of the asterisk operator to identify variants of the original words. The search strategy used in PubMed is presented in Table 1.

The aim was to find published and unpublished, primary and secondary studies, other types of articles, as well as content available in grey literature, in Portuguese, English or French, without time limitation. The searches were carried out in PubMed, CINAHL Complete, Psychology & Behavioral Sciences Collection, via EBSCOhost, and in the *Repositório Científico de Acesso Aberto de Portugal* (Open Scientific Portuguese Repository), in September 2024, by the main author with the support of a scientific librarian.

For the selection of evidence sources, all identified studies were integrated into the Rayyan and duplicates removed. Second, studies were selected according to title/abstract and full text reading, blindly by independent reviewers, using the defined criteria presented early in this section (eligibility criteria). Any disagreements in the selection process were discussed and a third reviewer was involved. In the final stage, the references of the articles selected in the previous stage were examined to determine the existence of additional and relevant literature within the reference criteria.

The data analysis process was carried out based on the review questions. Recurring concepts and patterns were identified across studies, providing a structured lens through which to address the research questions.

Results

Results are fully described in the report in a PRISMA diagram for selection of studies (Page et al., 2021), as presented in Fig. 1. Data was summarized in a table form to map the available and relevant knowledge about spirituality in children with life-limiting, life-threatening and/or complex chronic conditions. This mapping was conducted with regard to the following domains: the concept of spirituality; the needs and concerns of the children; the relationship between spirituality and illness; spiritual care; and topics for further research. In view of the subjectivity of the topic, objectives, and questions for this revision, data extraction was performed with an adaptation of the Template Study Details, Characteristics and Results Extraction Instrument for scoping reviews. The extraction was made with the intent to map scientific available evidence in extent, variety, and nature, as well as to identify topics which deserve further research (Tricco et al., 2016), related to the objectives and questions for this scoping review.

Table 1
Search strategy search conducted (September 2024), in PubMed.

Search	Query	Records retrieved
#1	(((spiritual*[Title] OR religi*[Title] OR "life philosophy"[Title] OR transcendence[Title] OR "meaning in life"[Title] OR hope[Title]) OR (Spirituality[MeSH Terms]) OR (Religion[MeSH Terms]) OR ("Spiritual Therapies"[MeSH Terms]) OR (hope[MeSH Terms]))	94,391
#2	(((("chronic condition"[Title] OR "chronic illness"[Title] OR "chronic disease"[Title] OR "life-threatening condition"[Title] OR "life-limiting condition"[Title] OR "life-threatening disease"[Title] OR "life-limiting disease"[Title] OR "life-threatening illness"[Title] OR "life-limiting illness"[Title] OR "palliative care"[Title] OR "end of life care"[Title] OR "terminal care"[Title] OR "hospice care"[Title] OR ("Chronic Disease"[MeSH Terms]) OR ("Palliative Care"[MeSH Terms]) OR ("Hospice and Palliative Care Nursing"[MeSH Terms])) OR ("Hospice Care"[MeSH Terms]) OR ("Terminal Care"[MeSH Terms]))	765,084
#3	((((((paediatric*[Title] OR pediatric*[Title] OR child*[Title] OR infant*[Title] OR newborn*[Title] OR teen*[Title] OR adolescen*[Title] OR young*[Title] OR (Pediatrics[MeSH Terms]) OR ("child, preschool"[MeSH Terms]) OR (Infant[MeSH Terms]) OR ("infant, newborn"[MeSH Terms]) OR (adolescent[MeSH Terms]) OR ("Young Adult"[MeSH Terms]))	4,566,040
#4 ((#1 AND #2 AND #3)	(((spiritual*[Title] OR religi*[Title] OR "life philosophy"[Title] OR transcendence[Title] OR "meaning in life"[Title] OR hope[Title]) OR (Spirituality[MeSH Terms]) OR (Religion[MeSH Terms]) OR ("Spiritual Therapies"[MeSH Terms]) OR (hope[MeSH Terms])) AND (((("chronic condition"[Title] OR "chronic illness"[Title] OR "chronic disease"[Title] OR "life-threatening condition"[Title] OR "life-limiting condition"[Title] OR "life-threatening disease"[Title] OR "life-limiting disease"[Title] OR "life-threatening illness"[Title] OR "life-limiting illness"[Title] OR "palliative care"[Title] OR "end of life care"[Title] OR "terminal care"[Title] OR "hospice care"[Title] OR ("Chronic Disease"[MeSH Terms]) OR ("Palliative Care"[MeSH Terms]) OR ("Hospice and Palliative Care Nursing"[MeSH Terms]) OR ("Hospice Care"[MeSH Terms]) OR ("Terminal Care"[MeSH Terms])) AND (((((paediatric*[Title] OR pediatric*[Title] OR child*[Title] OR infant*[Title] OR newborn*[Title] OR teen*[Title] OR adolescen*[Title] OR young*[Title] OR (Pediatrics[MeSH Terms]) OR ("child, preschool"[MeSH Terms]) OR (Infant[MeSH Terms]) OR ("infant, newborn"[MeSH Terms]) OR (adolescent[MeSH Terms]) OR ("Young Adult"[MeSH Terms]))	801

Characteristics and synthesis of sources of evidence

The final sample for this scoping review comprised 48 studies published between 2001 and 2024. Of these publications, six were theoretical papers, three were review articles, and three were book chapters. Twenty-one studies used qualitative methodologies, six used quantitative methodologies, six used a mixed-methods approach, and three were methodological studies.

The extraction of relevant information was summarized in a table, developed and adapted in alignment with the content on the Template Study Details, Characteristics and Results Extraction Instrument for scoping reviews, due to the specificity of the topic, objectives, and questions for this revision. See appendix 1.

Themes and subthemes

Given the diversity of study designs and outcomes, hybrid thematic analysis was used to synthesize the findings (Denzin et al., 2023). The data analysis process was carried out based on the review questions, combining deductive coding with data-driven inductive coding. Recurring concepts and patterns were identified across studies, providing a structured lens through which to address the research questions.

Theme 1: Concept representations

The concept is represented by the relationship established with oneself, with the outside world, and with representations that transcend reality (McPoland et al., 2024). It is a broad, highly individualised, and complex construct, thought with the potential to be masked along children’s agency, voice, maturity, and competence (Llewellyn et al., 2015). Spirituality is represented as a vehicle for growth on a path defined by the search for purpose, meaning, peace, hope (Barton et al., 2018; Grosseohme et al., 2020; Llewellyn et al., 2015), and amelioration of longing through connection (Pehler & Craft-Rosenberg, 2009). Also, it is a resource for dealing with the experience of living with the illness, making long-term adjustments (Reynolds et al., 2014), managing losses, and the early confrontation with death (McPoland et al., 2024).

Relationship with oneself

The connection with oneself is represented through self-awareness, which is manifested in one’s identity, dreams, goals, and way of living based on one’s values, and morals (Clayton-Jones et al., 2019).

Relationship with others, “the outside world”

The connection with the external world is represented through awareness of the world, which is manifested in one’s relationships, individual interests, and system of beliefs and values (Alvarenga et al., 2024; Clayton-Jones et al., 2016, 2019; Davies & Attig, 2012; Lyon et al., 2001). Children’s relationships with others - family, friends, animals, community, nature - are a relevant constituent (Llewellyn et al., 2015). Children’s spiritual and religious beliefs are capable of explaining the world and lived experiences (Cotton et al., 2009). It is described an awareness and knowledge implicit in each experience (Davies & Attig, 2012).

Relationship with nature, with the symbolic and/or sacred

The connection with the transcendent is represented through spiritual beliefs (forces of nature, human strength, and humanistic values), religious beliefs (Davies et al., 2002; Davies & Attig, 2012), and religious rituals, as experiences of healing (Lyon et al., 2001). Children talk about figures of supernatural and fictional origin (Cheng et al., 2024), about their beliefs in the afterlife, and about their relationships with deceased significant figures (Ferrell et al., 2016; Kamper et al., 2010). Adolescents’ relationship with the Divine may contribute to the development of self-concept, and change their way of thinking, living, and viewing experiences (Clayton-Jones et al., 2016). The connection with God may be a source of hope, comfort, wisdom, direction, faith, and strength (Clayton-Jones et al., 2016), associated with concepts of justice, benevolence, protection and security (Alvarenga et al., 2024).

Theme 2: Spiritual needs and concerns

Throughout the developmental trajectory with the illness, spiritual needs are usually manifested through behaviour, creative expression, and play (Clayton-Jones et al., 2016; Davies et al., 2002). These are related to challenges and concerns inherent in the real or potential loss of hope and meaning, in the disruption of normality, relationships, beliefs, and values (Llewellyn et al., 2015).

Spiritual needs throughout the course of illness

The spiritual needs throughout the course of illness are related to self-expression (Ferrell et al., 2016; Kamper et al., 2010; Liu, Ho, Lam, Lam, Cheng, Ching, & Wong, 2022); understand illness and related issues (McSherry et al., 2007); hope (Alvarenga, Machado, et al., 2021; Barton et al., 2018; Llewellyn et al., 2015); living life to the fullest/quality of life (Clayton-Jones et al., 2016, 2019; Kamper et al., 2010; Scott

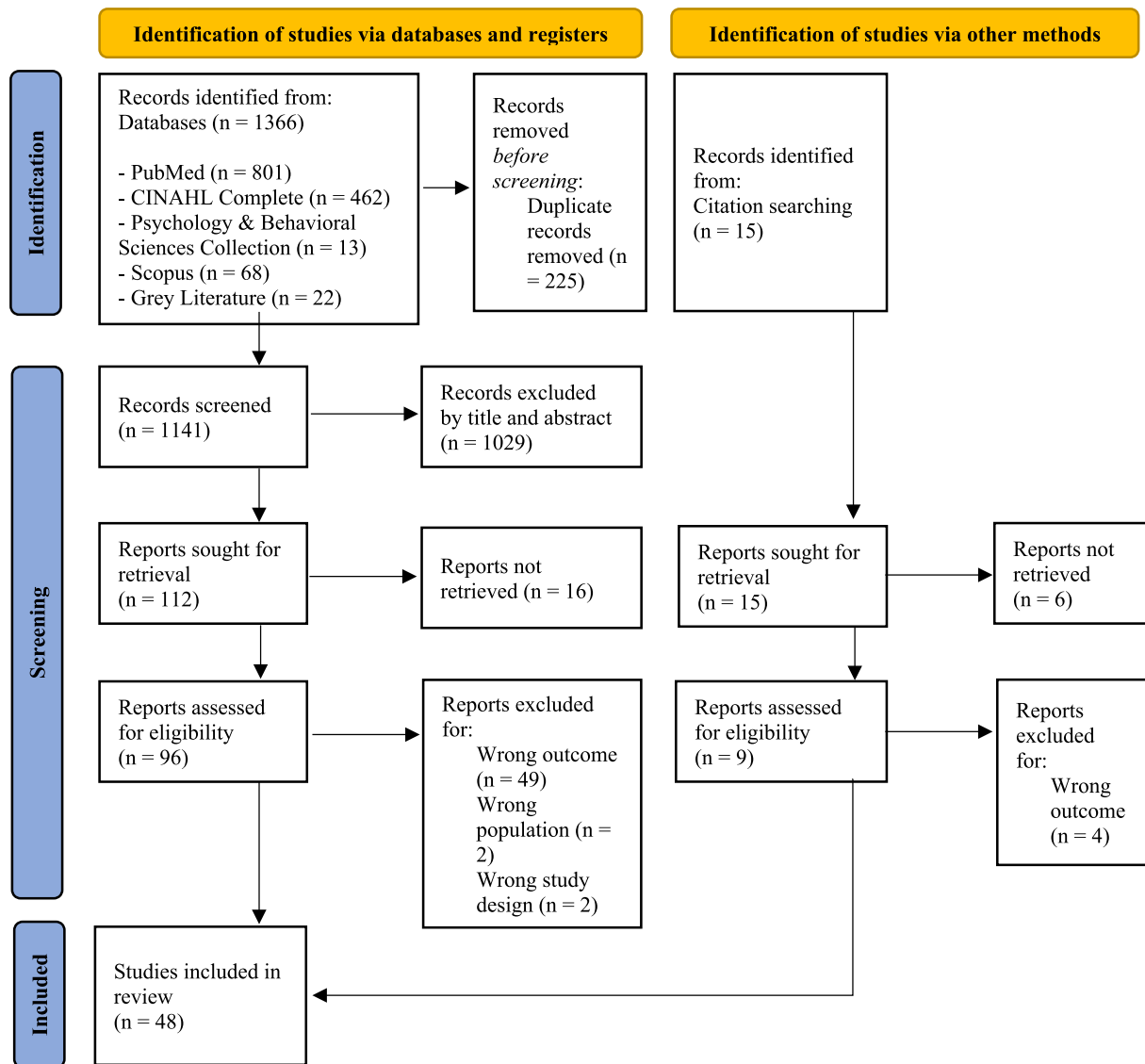


Fig. 1. PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources.

et al., 2023); meaning and purpose (Alvarenga, Machado, et al., 2021; Barton et al., 2018; Büssing et al., 2021; Davies et al., 2002; Foster et al., 2012; Llewellyn et al., 2015; Schaefer et al., 2021; Scott et al., 2023); benefit-finding (Schaefer et al., 2021); normality (Davies et al., 2002; Kamper et al., 2010; Llewellyn et al., 2015; Scott et al., 2023); relationships/connection with the external world (Alvarenga, Machado, et al., 2021; Büssing et al., 2021; Clayton-Jones et al., 2016; Kamper et al., 2010; Liu, Ho, Lam, Lam, Cheng, Ching, & Wong, 2022); acknowledgment and legacy (Clayton & Aldridge, 2019; Donnelly et al., 2005; Schaefer et al., 2021; Scott et al., 2023); altruism and caring for others (Kamper et al., 2010; Scott et al., 2023); expression of faith and religious beliefs (Alvarenga et al., 2024; Alvarenga, Machado, et al., 2021; Barton et al., 2018; Büssing et al., 2021; Clayton-Jones et al., 2016; Cotton et al., 2009; Donnelly et al., 2005; Ferrell et al., 2016; Juškauskienė et al., 2023; Kamper et al., 2010; Lyon et al., 2001). Specifically in adolescence, needs can be categorised into four domains with different and decreasing intensity of expression: positive attention, inner peace, existential, and/or religious needs (Büssing et al., 2021).

Spiritual concerns throughout the course of illness

The spiritual concerns throughout the course of illness are related to developmental experiences (McSherry et al., 2007; Scott et al., 2023);

uncertainty and disruptions (Llewellyn et al., 2015; Scott et al., 2023); feelings of guilt (Foster et al., 2012; Scott et al., 2023); fear of potential loneliness, rejection, loss of power, protection, and sense of belonging (Davies & Attig, 2012; Foster et al., 2012), and of experiencing the dying process of self and others (McPoland et al., 2024).

The spiritual needs and concerns at the end of life

The spiritual needs and concerns at the end of life are related to: losses of an anticipated bereavement (Davies & Attig, 2012); self-expression, fulfilment, authenticity, honesty, comfort, peace (Garvie et al., 2012), and reconciliation (Lyon et al., 2001); trusting relationships with healthcare providers (Lyon et al., 2001).

Theme 3: Relationship between spirituality and illness

The relationship established between spirituality and illness is described in a bidirectional way (Fig. 2), through a set of beliefs, practices, and mechanisms of spiritual adaptation. These contribute to meaning-making and management of loss in the experience of illness and premature death (Barton et al., 2018; Clayton-Jones et al., 2016; Damsma Bakker et al., 2018; de Souza et al., 2015; Llewellyn et al., 2015; McPoland et al., 2024); coping with everyday fears (Garvie et al.,

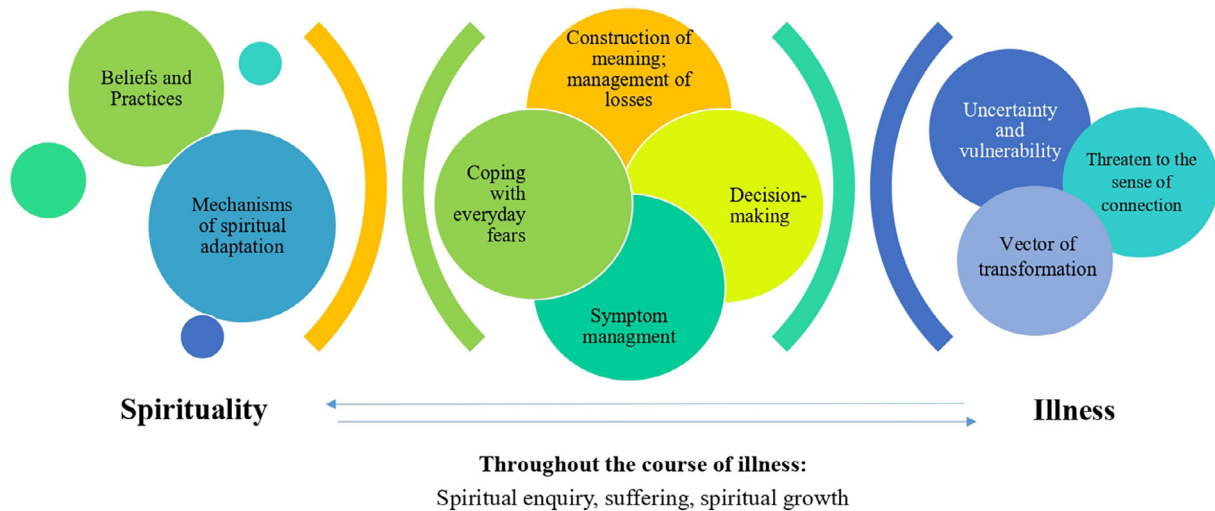


Fig. 2. Relationship established between spirituality and illness.

2012); symptom management (Cotton et al., 2009); decision-making in the healthcare context (Clayton-Jones et al., 2016; Cotton et al., 2009; Llewellyn et al., 2015).

On one hand, spirituality could function as a protective factor (Mistretta, 2017). On the other hand, illness brings uncertainty, and threatens the sense of connection (Davies & Attig, 2012). The experience of illness is a vector of transformation in the child's perception of their invulnerability (Davies & Attig, 2012). It takes greater relevance in understanding illness, and its meaning, than age or cognitive development (Davies & Attig, 2012), bringing the experience of spiritual enquiry, suffering and/or spiritual growth (Barton et al., 2018; Foster et al., 2012).

Spiritual coping

Spirituality is a source of coping (Clayton & Aldridge, 2019; Damsma Bakker et al., 2018). If spirituality is a source of meaning and peace throughout the course of illness, leading to positive coping strategies, then it may reduce the internalisation and externalisation of problems (Reynolds et al., 2013); be a protective factor against feelings of anxiety, depression, and behavioral problems related to the illness (Grossoehme et al., 2020; Mistretta, 2017; Reynolds et al., 2014); predict a lower use of maladaptive strategies, and negative spiritual coping (Reynolds et al., 2013, 2014, 2016).

On the other hand, negative spiritual coping strategies appear to contribute to internalisation of problems, lower quality of life, and poorer health status (Reynolds et al., 2016). It also appears to promote spiritual growth by increasing the use of positive spiritual coping mechanisms, such as seeking reconnection or spiritual collaboration. (Reynolds et al., 2014).

Spiritual beliefs and practices

Spiritual beliefs and practices function as resources (purpose, meaning, comfort, support, strength, hope, and well-being) during periods of significant challenge and difficulty (Alvarenga et al., 2024; Iannello et al., 2022; Juškauskienė et al., 2023). Also, spiritual beliefs can be reinforced by losses throughout the illness (McPoland et al., 2024).

Some adolescents may value the opportunity to explore their spirituality related to their illness (Grossoehme et al., 2020). Some may consider their spiritual beliefs and practices, as well as their relationship with God, as matters of a personal nature that should not be shared with others (Clayton-Jones et al., 2016).

Theme 4: Spiritual care

Conceptualized as “being there” (Llewellyn et al., 2015), and provided “in every detail” (Cheng et al., 2024), spiritual care is about creating a safe environment for spiritual questioning, particularly in times of challenge, difficulty, and terminal illness (Damsma Bakker et al., 2018; Davies & Attig, 2012; Foster et al., 2012; Llewellyn et al., 2015). It focuses on the ongoing presence of a trusted carer (Davies & Attig, 2012; Ferrell et al., 2016; Llewellyn et al., 2015); addresses the child's expressed needs in terms of their spirituality, other human dimensions and the illness itself (Alvarenga, Machado, et al., 2021; Ferrell et al., 2016); seems to be facilitated by time, as well as by a creative, respectful, and authentic presence (Khraisat et al., 2019); it takes into account developmental levels, and assessment and intervention tools and techniques that consider interaction, play, art, and artistic expression (Davies et al., 2002; Foster et al., 2012; Khraisat et al., 2019). These techniques help to restore a sense of power and possibility and reconnect individuals with their inner and outer worlds (Khraisat et al., 2019).

Spiritual care throughout the course of illness: the assessment

The assessment should be carried out on an ongoing basis, as the course of illness can change beliefs and values, by a trusted healthcare professional chosen by the child (Davies et al., 2002; Lyon et al., 2001). It is important to integrate factors related to the child's previous experiences, to recognize the context, religious idioms, and secular ritual practices (Lyon et al., 2001), to attend to the family's communication, and the social context/support (Foster et al., 2012).

The assessment focuses on open questions and observation of clues/behaviours related to spiritual needs and concerns, experiences, thoughts, traditions, rituals, and beliefs (Davies et al., 2002; McSherry et al., 2007), fears and expectations (Cheng et al., 2024; Davies et al., 2002). Guidelines, open ended questions, and a set of behaviours and responses for addressing spiritual needs and concerns are presented by Davies et al. (2002), McSherry et al. (2007), and Büssing et al. (2021). A framework (Spiritual Development Framework) is presented as a valuable guide, providing adolescents with opportunities to search for meaning in their experiences by actively participating in research and care (Clayton-Jones et al., 2019).

The reliable and valid evaluation instruments identified in the context of this review: the Spiritual Needs Questionnaire (Büssing, 2021); the Functional Assessment of Chronic Illness Therapy - Spiritual Well-

Being 12 Item Scale (Alvarenga et al., 2022; Liu, Ho, Lam, Lam, Cheng, Ching, Belay, & Wong, 2022); the spiritual Quality of Life Questionnaire (Kamper et al., 2010); the McBride Spirituality Assessment (Farrell et al., 2008).

Spiritual care throughout the course of illness: the intervention

Throughout the development process, the intervention focuses on acknowledging/addressing children's spiritual experiences, needs, and concerns, search for meaning, and fostering connections (Barton et al., 2018; Cheng et al., 2024; Donnelly et al., 2005; Foster et al., 2012; Juškauskienė et al., 2023; Llewellyn et al., 2015; McSherry et al., 2007); setting achievable goals and a legacy (Davies & Attig, 2012; Foster et al., 2012; Scott et al., 2023); managing losses and redefining hope (Davies et al., 2002; Llewellyn et al., 2015); alleviating spiritual suffering (Cheng et al., 2024; Foster et al., 2012); mediating communication between children and families (Foster et al., 2012; Garvie et al., 2012; Llewellyn et al., 2015); involving the child in decision-making (Davies & Attig, 2012); referring to specialised professionals, such as chaplaincy professionals and spiritual counsellors (Lion et al., 2019; Pouy et al., 2024; Reynolds et al., 2016); encouraging the presence of children and young people with similar past experiences (Llewellyn et al., 2015); intervening in the presence of negative spiritual coping (highlights children's spiritual needs) and supporting positive spiritual coping (Damsma Bakker et al., 2018).

The following are specific ways of intervening with children that may be included in the domain of spiritual care: the photo-elicitation interview and intervention, which may facilitate the exploration of spirituality and spiritual experiences (Alvarenga et al., 2024; Alvarenga, Leite, et al., 2021); the construct sanctification of the body construct, which may be a construct with potential applications in care and self-care (Grossoehme et al., 2008); specific poetry, which may help healthcare professionals connect with children and help children express their questions and spiritual concerns (Calandrino, 2023); Godly Play, an activity involving storytelling followed by creative play based on the meaning of the story, which may strengthen the child's spirituality in challenging periods (Farrell et al., 2008); Reiki, complementary "light touch therapy", which may contribute to feelings of happiness, comfort, relaxation, and quality of life (Thrane et al., 2021, 2022).

Spiritual care at the end of life: the assessment and intervention

At the end of life, a relationship based on trust and high-quality care should help children to grow spiritually, and to have a peaceful death (Petersen, 2014). It is important to assess existential questions, spiritual anguish, and spiritual needs, and support self-expression, closeness in relationships, meaning-making, hope, and legacy (Davies et al., 2002; Petersen, 2014). The Wish Fulfilment is an intervention which may contribute to the sense of normality, as it allows the child to dream, keep developing, and fulfil themselves (Ewing, 2009).

Theme 5: Thematic evidence that requires future research

In terms of thematic evidence that requires further research, it seems important to examine spiritual coping and explore effective approaches to spiritual assessment/care in children (Drutchas & Anandarajah, 2014); construct valid tools to assess spiritual needs and concerns (Kamper et al., 2010); assess and evaluate clinical interventions targeting specific spiritual needs. (Büssing, 2021; Drutchas & Anandarajah, 2014); identify preferences for discussing spirituality in a health context (Cotton et al., 2009); explore spiritual experiences and spiritual coping at the end of life stage in specific populations (Mistretta, 2017); develop and empirically evaluating interventions that explore the role of spiritual coping in adjustment and its potential for change (Reynolds et al., 2013, 2014); explore the mechanisms between spirituality and expectations of health outcomes (Iannello et al., 2022); identify ways to address hope and expectations in the context

of paediatric palliative care (Llewellyn et al., 2015); develop evidence in the area of managing spiritual distress, particularly in dying children (Foster et al., 2012); develop palliative interventions that address meaning-making, including the spiritual dimension as a novel focus for intervention (Grossoehme et al., 2020).

Discussion

This review identified and synthesized the available knowledge on spirituality in children living with life-limiting, life-threatening, and/or complex chronic conditions. It incorporated multiple perspectives within a context in which experiences, needs, and concerns are highly individual and often shaped by daily gains and losses, whether real or potential. In this context, the spiritual dimension assumes a preponderant and aggregating place. This is consistent with the conceptualisation of spirituality as a potential modifier and restructurer of other aspects during the developmental process (Burgueño López et al., 2024).

Also, the results of the present study appear to provide further evidence in support of the concept of children's spirituality as a "relational consciousness" (Hay & Nye, 2006), a concept which is similarly upheld by the qualitative meta-synthesis, made by Damsma Bakker et al. (2018), entitled "The spirituality of children with chronic conditions: A qualitative meta-synthesis". For children with life-limiting, life-threatening, and complex chronic conditions, spirituality is characterized by the notion of interconnectedness. This is characterized by the cultivation of self-awareness, recognition of others, and a comprehensive understanding of the world.

Children's spiritual needs and concerns appear to be primarily related to their developmental stage, their need to connect with others, their need to express themselves, and their search for meaning. In this context, meaning encompasses the knowledge children acquire through their experiences of illness, and the interpretations they ascribe to these experiences. Also, it encompasses the things that give significance to their lives in the present moment.

Children seek wholeness in the absence of a cure and given the unpredictable nature of the illness (Scott et al., 2023). They are open to living with uncertainty in the present and leaving a legacy for those who are important to them (Clayton & Aldridge, 2019). Nevertheless, they need to continue growing, developing, and making plans for the future, even during illness and at the end of life. They should remain "engaged with life in potentially joyful ways" (McSherry et al., 2007, pp. 618). Family, the "spiritual foundation" (Clayton-Jones et al., 2016, pp. 694), friends, and healthcare professionals all seem to play a significant role in responding to the specific spiritual needs and concerns of children.

On the other hand, children naturally seek to understand their existence in order to give their lives meaning and purpose (Ferrell et al., 2016). Children process and respond with their own insights to the experience of illness, dying, and death (Clayton & Aldridge, 2019). The relationship established between spirituality and illness translates the process of spiritual growth, adaptation, and transformation experienced during childhood within a religious or spiritual context. The experience of illness is a vector of transformation: a visible threat to "the taken-for-granted patterns of (...) daily lives" (Davies & Attig, 2012, pp. 262), and a vehicle for developing a spiritual identity, where responsibility and connectedness, to others and the world, take a greater role (Alvarenga et al., 2024).

Children try to find their own way of living, interconnect, and belong within a sociocultural context. Along the journey of spiritual development, healthy and/or harmful outcomes may arise from change in time, growth, and significant experiences of children (Roehlkepartain et al., 2008).

In this context, spirituality can provide a foundation for redefining meaning, coping with losses, and making healthcare decisions. However, as previously described by Damsma Bakker et al. (2018), children may experience negative effects on their health and ability to cope with

illness, as well as a poorer quality of life, if spirituality does not provide meaning and peace, or if spiritual questioning and coping mechanisms are not practised in a healthy way.

Understanding the specific spiritual needs and concerns of children living with complex, life-limiting, and/or life-threatening chronic illnesses is imperative, both for their quality of life and the quality of their care (Benini et al., 2022; Chambers, 2018). Spiritual care for children with life-limiting, life-threatening and complex chronic conditions is defined by the quality of an authentic, creative, and respectful presence over time.

As the Royal College of Nursing states, it is about being in care with someone (Royal College of Nursing, 2011). It develops through a compassionate relationship that is open to recognizing and responding to the unique expression of each human spirit, and its real needs (NHS Education for Scotland, 2021). It translates into moments of active and sensitive listening, support for meaning, self-expression, and self-esteem (NHS Education for Scotland, 2021; Royal College of Nursing, 2011).

Children translate what they are living through art and play (Clayton & Aldridge, 2019). As Khraisat et al., (2019, pp. 614) state, “arts empower children to use their basic human energy to create a sense of possibility (...) a feeling of wholeness”. It is essential that healthcare professionals create a safe environment that is open to dialogue and facilitates self-expression in creative ways. Expression and its recognition make it possible to find a way to give meaning and hope to life (Davies & Attig, 2012; Llewellyn et al., 2015). Even at the end of life, children appear to seek ways to experience the remaining time as valuable, meaningful, and hopeful. This can be facilitated by healthcare professionals who acknowledge their spiritual needs and create a supportive environment (Davies & Attig, 2012).

Strengths and limitations

As limitations, we highlight the fact that most studies were conducted with a sample characterized by a varied set of clinical conditions and were predominantly developed in the United States of America. The broad spectrum of developmental stages; clinical conditions; phases of the disease process; healthcare contexts; family; sociocultural and religious contexts; and the methodologies employed to conduct the studies, constituted a considerable challenge to the organisation, relationship, and description of results.

This reflects not only the complexity and variability of how the concept of spirituality applies to the paediatric population, but also underscores the urgency of developing empirical studies in the field of spirituality and spiritual care. There is a clear necessity for research that provides greater attributive and relational specificity, moving beyond the current tendency toward generalization through associative links between variables.

Therefore, it is evident that further research is required to improve understanding of the concept and care for specific population groups within this larger group of children, and adolescents. Furthermore, it could be suggested that research in this field be developed with a broader concept, as has already been done with parents by Miquel et al. (2024). This would include the concept of life philosophy to capture the uniqueness of each experience in a secularised society with a broad spectrum of spiritual beliefs and practices (Miquel et al., 2024).

Implications to practice

Children's spiritual dimension is a vital aspect of holistic care that must not be overlooked (Donnelly et al., 2005; Farrell et al., 2008). Acknowledgement, empathy, counselling, and caring are crucial elements (Alvarenga, Machado, et al., 2021; Donnelly et al., 2005).

Healthcare providers should listen to children, provide them with information, and help them to gain insight into their beliefs, values, and behaviours; facilitate spiritual exploration, and address needs and

concerns inherent in the developmental process; set achievable developmental goals that can support a meaningful life and legacy; help children to acknowledge and manage losses, redefine faith and hope, and alleviate spiritual suffering; support children in fostering connections, facilitating communication, and improving positive spiritual coping mechanisms to enhance psychological well-being during illness.

Conclusion

The main aim of this scoping review was to map the available evidence in the literature on the spirituality of children, adolescents, and young adults with complex, life-limiting, and/or life-threatening chronic conditions. Encompassing multiple perspectives, the review presents ample and well-founded evidence that underlines the complexity, variability, and importance of spirituality while living within a paediatric complex context. Also, it supports the imperative to develop and nurture the spiritual dimension in the care of these children. Given the heightened vulnerability inherent in the health-illness continuum, and its significance within the therapeutic relationship (Cuartas-Hoyos et al., 2023), attending to the particularities of these children's spirituality is imperative in order to improve their quality of life and the quality of care.

Although this review presents a wide range of content, there is still an urgent need to develop studies on the concept of spirituality and spiritual care in specific subgroups of this paediatric population, according to developmental stage, age and clinical condition.

The spiritual lives of children with complex, life-limiting, and/or life-threatening chronic conditions reflect their search for wholeness, purpose, meaning, and hope, as well as their deep connection to their inner experiences and the external world. Their spiritual needs and concerns reveal how spirituality and illness are intertwined, influencing each other throughout a child's illness. These needs and concerns often emerge in response to the challenges of loss, disruption, and uncertainty. In these contexts spirituality can be a resource for growth, meaning-making, and coping. Thus, in complex paediatric contexts, spirituality and spiritual care should be recognized as a core component of holistic care and prioritised in care plans.

CRedit authorship contribution statement

Mónica dos Santos Ferreira: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Diana Gomes Pereira:** Writing – review & editing, Visualization, Validation, Supervision, Resources, Methodology, Investigation, Formal analysis, Data curation. **Sílvia Caldeira:** Writing – review & editing, Visualization, Validation, Supervision, Resources, Methodology, Formal analysis, Data curation, Conceptualization.

Declaration of generative AI and AI-assisted technologies in the writing process

English is not the primary language of the authors. During the preparation of this work the authors used DeepL and Grammarly to improve the structure and translation of some sentences. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the published article.

Funding sources

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Declaration of competing interest

All the authors have no conflict of interest to declare.

Acknowledgments

Library Services of the Portuguese Catholic University.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pedn.2025.11.031>.

References

- Alvarenga, W. A., Carvalho, E. C., Caldeira, S., Vieira, M., & Nascimento, L. C. (2017). The possibilities and challenges in providing pediatric spiritual care. *Journal of Child Health Care*, 21(4), 435–445. <https://doi.org/10.1177/1367493517737183>.
- Alvarenga, W. A., Cruz, I. E. C., Leite, A. C. A. B., Machado, J. R., Santos, L. B. P. A., de Lima, R. A. G., & Nascimento, L. C. (2024). "God gives me hope!": Hospitalized children's perception of the influence of religion in coping with chronic illness. *Journal of Pediatric Nursing*, 77, 13–20. <https://doi.org/10.1016/j.pedn.2024.02.022>.
- Alvarenga, W. A., Leite, A. C. A. B., Menochelli, A. A., Ortiz La Banca, R., Bortoli, P. S., Neris, R. R., & Nascimento, L. C. (2021). How to talk to children and adolescents with cancer about spirituality? Establishing a conversation model. *Journal of Pediatric Oncology Nursing*, 38(2), 116–130. <https://doi.org/10.1177/1043454220975703>.
- Alvarenga, W. A., Machado, J. R., Leite, A. C. A. B., Caldeira, S., Vieira, M., Rocha, S. S., & Nascimento, L. C. (2021). Spiritual needs of Brazilian children and adolescents with chronic illnesses: A thematic analysis. *Journal of Pediatric Nursing*, 60, e39–e45. <https://doi.org/10.1016/j.pedn.2021.02.020>.
- Alvarenga, W. A., Nascimento, L. C., Rebustini, F., Santos, C. B., Muehlan, H., Schmidt, S., ... Vieira, M. (2022). Evidence of validity of internal structure of the functional assessment of chronic illness therapy-spiritual well-being scale (FACT-Sp-12) in Brazilian adolescents with chronic health conditions. *Frontiers in Psychology*, 13 Article 991771. <https://doi.org/10.3389/fpsyg.2022.991771>.
- Barton, K. S., Tate, T., Lau, N., Taliesin, K. B., Waldman, E. D., & Rosenberg, A. R. (2018). "I'm not a spiritual person". How hope might facilitate conversations about spirituality among teens and young adults with cancer. *Journal of Pain and Symptom Management*, 55(6), 1599–1608. <https://doi.org/10.1016/j.jpainsymman.2018.02.001>.
- Benini, F., Papadatou, D., Bernadà, M., Craig, F., De Zen, L., Downing, J., ... Wolfe, J. (2022). International standards for pediatric palliative care: From IMPaCCT to GO-PPaCS. *Journal of Pain and Symptom Management*, 63(5), e529–e543. <https://doi.org/10.1016/j.jpainsymman.2021.12.031>.
- Burgueño López, J., Torre Puente, J. C., & Sanz, B. U. (2024). Approaching a conceptualisation of the spiritual dimension: The need for its development from the initial stages of a person's formation. *International Studies in Catholic Education*, 0(0), 1–14. <https://doi.org/10.1080/19422539.2024.2387690>.
- Büssing, A. (2021). Adapted spiritual needs questionnaire for adolescents with chronic diseases. In A. Büssing (Ed.), *Spiritual needs in research and practice: The spiritual needs questionnaire as a global resource for health and social care* (pp. 103–110). Springer International Publishing. https://doi.org/10.1007/978-3-030-70139-0_8.
- Büssing, A., Hussong, J., Große-Onnebrink, J., & von Gontard, A. (2021). Spiritual needs of adolescents with chronic diseases. In A. Büssing (Ed.), *Spiritual needs in research and practice: The spiritual needs questionnaire as a global resource for health and social care* (pp. 297–311). Springer International Publishing. https://doi.org/10.1007/978-3-030-70139-0_22.
- Calandrino, A. (2023). End of life in pediatrics: The "relief" of poetry on pain by reaching children's spirituality. *Journal of Pain and Symptom Management*, 66(3), e443–e447. <https://doi.org/10.1016/j.jpainsymman.2022.10.015>.
- Chambers, L. (2018). A guide to children's palliative care. *Together for short lives*. <https://www.togetherforshortlives.org.uk/resource/a-guide-to-childrens-palliative-care/>.
- Cheng, L., Cai, S., Zhou, X., & Zhai, X. (2024). In every detail: Spiritual care in pediatric palliative care perceived by healthcare providers. *Journal of Pain and Symptom Management*, 67(2), 167–172. <https://doi.org/10.1016/j.jpainsymman.2023.11.005>.
- Clayton, M., & Aldridge, J. (2019). Fifteen-minute consultation: Not the whole story—considering children's spirituality and advance care planning. *Archives of Disease in Childhood: Education and Practice Edition*, 104(4), 170–172. <https://doi.org/10.1136/archdischild-2017-314525>.
- Clayton-Jones, D., Haglund, K., Belknap, R. A., Schaefer, J., & Thompson, A. A. (2016). Spirituality and religiosity in adolescents living with sickle cell disease. *Western Journal of Nursing Research*, 38(6), 686–703. <https://doi.org/10.1177/0193945915625065>.
- Clayton-Jones, D., Haglund, K. A., Schaefer, J., Koinig, H. G., & George Dalmida, S. (2019). Use of the spiritual development framework in conducting spirituality and health research with adolescents. *Journal of Religion and Health*, 58(4), 1259–1271. <https://doi.org/10.1007/s10943-018-00752-z>.
- Coles, R. (1991). *The spiritual life of children*. Houghton Mifflin Harcourt.
- Connor, S. R., Downing, J., & Marston, J. (2017). Estimating the global need for palliative care for children: A cross-sectional analysis. *Journal of Pain and Symptom Management*, 53(2), 171–177. <https://doi.org/10.1016/j.jpainsymman.2016.08.020>.
- Cotton, S., Grosseohme, D., Rosenthal, S. L., McGrady, M. E., Roberts, Y. H., Hines, J., ... Tsevat, J. (2009). Religious/spiritual coping in adolescents with sickle cell disease: A pilot study. *Journal of Pediatric Hematology/Oncology*, 31(5), 313–318. <https://doi.org/10.1097/MPH.0b013e31819e40e3>.
- Cuartas-Hoyos, P., Charry Hernandez, R., & Ospina-Muñoz, P. (2023). Cuidado espiritual: Una mirada desde el manejo de síntomas y el cuidado paliativo. *Revista Colombiana de Enfermería*, 18(1) Article e005. <https://doi.org/10.18270/rce.v18i1.2341>.
- Damsma Bakker, A., van Leeuwen, R., & Roodbol, P. (2018). The spirituality of children with chronic conditions: A qualitative meta-synthesis. *Journal of Pediatric Nursing*, 43, e106–e113. <https://doi.org/10.1016/j.pedn.2018.08.003>.
- Davies, B., & Attig, T. (2012). Caring for children in hospice and palliative care: The spiritual/religious dimension. In H. Coward, & K. I. Stajduhar (Eds.), *Religious understandings of a good death in hospice palliative care* (pp. 257–275). State University of New York Press.
- Davies, B., Brenner, P., Orloff, S., Sumner, L., & Worden, W. (2002). Addressing spirituality in pediatric hospice and palliative care. *Journal of Palliative Care*, 18, 59–67. <https://doi.org/10.1177/082585970201800109>.
- Denzin, N. K., Lincoln, Y. S., Giardina, M. D., & Cannella, G. S. (Eds.). (2023). *The SAGE handbook of qualitative research* (6th ed.). SAGE Publications.
- Donnelly, J. P., Huff, S. M., Lindsey, M. L., McMahon, K. A., & Schumacher, J. D. (2005). The needs of children with life-limiting conditions: A healthcare-provider-based model. *The American Journal of Hospice & Palliative Care*, 22(4), 259–267. <https://doi.org/10.1177/104990910502200406>.
- Drutchas, A., & Anandarajah, G. (2014). Spirituality and coping with chronic disease in pediatrics. *Rhode Island Medical Journal* (2013), 97(3), 26–30. <https://pubmed.ncbi.nlm.nih.gov/24596927/>.
- Ewing, B. (2009). *Wish fulfillment: Palliative care and end-of-life intervention*. *Pediatric Nursing*, 35(2), 81–85.
- Farrell, J., Cope, S. B., Cooper, J. H., & Mathias, L. (2008). Godly play: An intervention for improving physical, emotional, and spiritual responses of chronically ill hospitalized children. *The Journal of Pastoral Care & Counseling*, 62(3), 261–271. <https://doi.org/10.1177/154230500806200307>.
- Ferrell, B., Wittenberg, E., Battista, V., & Walker, G. (2016). Nurses' experiences of spiritual communication with seriously ill children. *Journal of Palliative Medicine*, 19(11), 1166–1170. <https://doi.org/10.1089/jpm.2016.0138>.
- Foster, T. L., Bell, C. J., & Gilmer, M. J. (2012). Symptom management of spiritual suffering in pediatric palliative care. *Journal of Hospice & Palliative Nursing*, 14(2), 109–115. <https://doi.org/10.1097/NJH.0b013e3182491f4b>.
- Garvie, P. A., He, J., Wang, J., D'Angelo, L. J., & Lyon, M. E. (2012). An exploratory survey of end-of-life attitudes, beliefs and experiences of adolescents with HIV/AIDS and their families. *Journal of Pain and Symptom Management*, 44(3), 373–385, e29. <https://doi.org/10.1016/j.jpainsymman.2011.09.022>.
- Gijsberts, M. J. H. E., Liefbroer, A. I., Otten, R., & Olsman, E. (2019). Spiritual care in palliative care: A systematic review of the recent European literature. *Medical Sciences (Basel, Switzerland)*, 7(2), 25. <https://doi.org/10.3390/medsci7020025>.
- Grosseohme, D. H., Frieber, S., Baker, J. N., Tweddle, M., Needle, J., Chrastek, J., ... Lyon, M. E. (2020). 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. *JAMA Network Open*, 3(6) Article e206696. <https://doi.org/10.1001/jamanetworkopen.2020.6696>.
- Grosseohme, D. H., VanDyke, R., & Seid, M. (2008). Spirituality's role in chronic disease self-management: Sanctification of the body in families dealing with cystic fibrosis. *Journal of Health Care Chaplaincy*, 15(2), 149–158. <https://doi.org/10.1080/08854720903163312>.
- Hay, D., & Nye, R. (2006). *The spirit of the child: Revised edition*. Jessica Kingsley Publishers.
- Iannello, N. M., Inguiglia, C., Silletti, F., Albiero, P., Cassibba, R., Lo Coco, A., & Musso, P. (2022). How do religiosity and spirituality associate with health-related outcomes of adolescents with chronic illnesses? A scoping review. *International Journal of Environmental Research and Public Health*, 19(20) Article 13172. <https://doi.org/10.3390/ijerph192013172>.
- Jackson, S. (2012). Children, spirituality, and counselling. *American Journal of Applied Psychology*, 1(1), 1–5. <https://doi.org/10.11648/jajap.20120101.11>.
- Juškauskienė, E., Rikikiškienė, O., & Fisher, J. (2023). Spiritual well-being and related factors in children with cancer. *Journal of Pediatric Hematology/Oncology Nursing*, 40(6), 420–431. <https://doi.org/10.1177/27527530231168592>.
- Kamper, R., Van Cleve, L., & Savedra, M. (2010). Children with advanced cancer: Responses to a spiritual quality of life interview. *Journal for Specialists in Pediatric Nursing*, 15(4), 301–306. <https://doi.org/10.1111/j.1744-6155.2010.00253.x>.
- Khrasat, O., Alkhalwaleh, A., & Abuhammad, S. (2019). Spirituality-focused end-of-life care among paediatric patients: Evidence from Saudi Arabia. *International Journal of Palliative Nursing*, 25, 610–616. <https://doi.org/10.12968/ijpn.2019.25.12.610>.
- Lion, A. H., Skiles, J. L., Watson, B. N., Young, J. D., & Torke, A. M. (2019). Chaplain care in pediatric oncology: Insight for interprofessional collaboration. *Pediatric Blood & Cancer*, 66(12) Article e27971. <https://doi.org/10.1002/pbc.27971>.
- Liu, Q., Ho, K. Y., Lam, K. K. W., Lam, W. Y. Y., Cheng, E. H. L., Ching, S. S. Y., & Wong, F. K. Y. (2022). A descriptive and phenomenological exploration of the spiritual needs of Chinese children hospitalized with cancer. *International Journal of Environmental Research and Public Health*, 19(20) Article 13217. <https://doi.org/10.3390/ijerph192013217>.
- Liu, Q., Ho, K. Y., Lam, K. K. W., Lam, W., Cheng, E. H. L., Ching, S. S. Y., ... Wong, F. K. Y. (2022). Adaptation and psychometric evaluation of the Chinese version of the functional assessment of chronic illness therapy spiritual well-being scale among Chinese childhood cancer patients in China. *Frontiers in Psychology*, 13 Article 1065854. <https://doi.org/10.3389/fpsyg.2022.1065854>.
- Llewellyn, H., Jones, L., Kelly, P., Barnes, J., O'Gorman, B., Craig, F., & Bluebond-Langner, M. (2015). Experiences of healthcare professionals in the community dealing with the spiritual needs of children and young people with life-threatening and life-limiting conditions and their families: Report of a workshop. *BMJ Supportive & Palliative Care*, 5(3), 232–239. <https://doi.org/10.1136/bmjspcare-2012-000437>.
- Lyon, M. E., Townsend-Akpan, C., & Thompson, A. (2001). Spirituality and end-of-life care for an adolescent with AIDS. *AIDS Patient Care and STDs*, 15(11), 555–560. <https://doi.org/10.1089/108729101753287630>.

- McPoland, P., Grosseohme, D. H., Sheehan, D. C., Stephenson, P., Downing, J., Deshommes, T., ... Frieber, S. (2024). Children's understanding of dying and death: A multinational grounded theory study. *Palliative & Supportive Care*, 22(2), 213–220. <https://doi.org/10.1017/S1478951523000287>.
- McSherry, M., Kehoe, K., Carroll, J. M., Kang, T. I., & Rourke, M. T. (2007). Psychosocial and spiritual needs of children living with a life-limiting illness. *Pediatric Clinics of North America*, 54(5), 609–629 ix–x. <https://doi.org/10.1016/j.pcl.2007.08.002>.
- Miquel, P., Clemente, I., & Ciccorossi, M. (2024). Exploring spirituality, religion and life philosophy among parents of children receiving palliative care: A qualitative study. *BMC Palliative Care*, 23(1), 43. <https://doi.org/10.1186/s12904-024-01345-2>.
- Mistretta, E. G. (2017). Spirituality in young adults with end-stage cancer: A review of the literature and a call for research. *Annals of Palliative Medicine*, 6(3), 279–283. <https://doi.org/10.21037/apm.2017.06.17>.
- Nasir, A., Nasir, L., Tarrell, A., Finken, D., Lacroix, A., Pinninti, S., Pitner, S., & McCarthy, M. (2018). Complexity in pediatric primary care. *Primary Health Care Research & Development*, 20 Article e59. <https://doi.org/10.1017/S146342361800035X>.
- NHS Education for Scotland (2021). Spiritual care matters: An introductory resource for all NHS Scotland staff. <https://www.nes.scot.nhs.uk/our-work/spiritual-care/>.
- Nolan, S., Saltmarsh, P., & Leget, C. (2011). *Spiritual care in palliative care: Working towards an EAPC task force*. European Public Law, 18. https://www.researchgate.net/publication/254777253_Spiritual_care_in_palliative_care_Working_towards_an_EAPC_Task_Force#fullTextFileContent.
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *British Medical Journal*, 372, Article 89. <https://doi.org/10.1136/bmj.n71>.
- Pehler, S. R., & Craft-Rosenberg, M. (2009). Longing: The lived experience of spirituality in adolescents with duchenne muscular dystrophy. *Journal of Pediatric Nursing*, 24(6), 481–494. <https://doi.org/10.1016/j.pedn.2008.06.008>.
- Peters, M. D., Godfrey, C., McInerney, P., Munn, Z., Tricco, A. C., & Khalil, H. (2024). Scoping reviews. In E. Aromataris, C. Lockwood, K. Porritt, B. Pilla, & Z. Jordan (Eds.), *JBI manual for evidence synthesis*. Joanna Briggs Institute. <https://doi.org/10.46658/JBIMES-24-09>.
- Petersen, C. L. (2014). Spiritual care of the child with cancer at the end of life: A concept analysis. *Journal of Advanced Nursing*, 70(6), 1243–1253. <https://doi.org/10.1111/jan.12257>.
- Pouy, S., Taheri, Z., Rassouli, M., Darbandi, B., & Javadi-Pashaki, N. (2024). Unmet needs of palliative care among iranian children with cancer and their families: A qualitative study. *International Journal of Cancer Management*, 16, 1–10. <https://doi.org/10.5812/ijcm-136251>.
- Reynolds, N., Mrug, S., & Guion, K. (2013). Spiritual coping and psychosocial adjustment of adolescents with chronic illness: The role of cognitive attributions, age, and disease group. *Journal of Adolescent Health*, 52(5), 559–565. <https://doi.org/10.1016/j.jadohealth.2012.09.007>.
- Reynolds, N., Mrug, S., Hensler, M., Guion, K., & Madan-Swain, A. (2014). Spiritual coping and adjustment in adolescents with chronic illness: A 2-year prospective study. *Journal of Pediatric Psychology*, 39(5), 542–551. <https://doi.org/10.1093/jpepsy/jsu011>.
- Reynolds, N., Mrug, S., Wolfe, K., Schwebel, D., & Wallander, J. (2016). Spiritual coping, psychosocial adjustment, and physical health in youth with chronic illness: A meta-analytic review. *Health Psychology Review*, 10(2), 226–243. <https://doi.org/10.1080/17437199.2016.1159142>.
- Roehlkepartain, E. C., Benson, P. L., Scales, P. C., Kimball, L., & King, P. E. (2008). *With their own voices a global exploration of how today's young people experience and think about spiritual development*. Center for Spiritual Development in Childhood and Adolescence. https://www.search-institute.org/wp-content/uploads/2018/02/with_their_own_voices_report.pdf.
- Royal College of Nursing (2011). *Spirituality in nursing care: A pocket guide*. RCN.
- Schaefer, M. R., Kenney, A. E., Himelhoch, A. C., Howard Sharp, K. M., Humphrey, L., Olshefski, R., ... Gerhardt, C. A. (2021). A quest for meaning: A qualitative exploration among children with advanced cancer and their parents. *Psycho-Oncology*, 30(4), 546–553. <https://doi.org/10.1002/pon.5601>.
- Scott, H. M., Coombes, L., Braybrook, D., Roach, A., Harðardóttir, D., Bristowe, K., ... Harding, R. (2023). Spiritual, religious, and existential concerns of children and young people with life-limiting and life-threatening conditions: A qualitative interview study. *Palliative Medicine*, 37(6), 856–865. <https://doi.org/10.1177/02692163231165101>.
- Smith, J., & McSherry, W. (2004). Spirituality and child development: A concept analysis. *Journal of Advanced Nursing*, 45(3), 307–315. <https://doi.org/10.1046/j.1365-2648.2003.02891.x>.
- de Souza, V. M., Frizzo, H. C. F., de Paiva, M. H. P., Bousso, R. S., & da Silva Santos, A. (2015). Spirituality, religion and personal beliefs of adolescents with cancer. *Revista Brasileira de Enfermagem*, 68(5), 509–514. <https://doi.org/10.1590/0034-7167.2015680504i>.
- Thrane, S. E., Maurer, S. H., & Danford, C. A. (2021). Feasibility and acceptability of reiki therapy for children receiving palliative care in the home. *Journal of Hospice and Palliative Nursing*, 23(1), 52–58. <https://doi.org/10.1097/NJH.0000000000000714>.
- Thrane, S. E., Williams, E., Grosseohme, D. H., & Frieber, S. (2022). Reiki therapy for very young hospitalized children receiving palliative care. *Journal of Pediatric Hematology/Oncology Nursing*, 39(1), 15–29. <https://doi.org/10.1177/27527530211059435>.
- Timmins, F., & Caldeira, S. (2017). Understanding spirituality and spiritual care in nursing. *Nursing Standard*, 31(22), 50–57. <https://doi.org/10.7748/ns.2017.e10311>.
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K., Colquhoun, H., Kastner, M., ... Straus, S. E. (2016). A scoping review on the conduct and reporting of scoping reviews. *BMC Medical Research Methodology*, 16, 15. <https://doi.org/10.1186/s12874-016-0116-4>.
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., ... Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473. <https://doi.org/10.7326/M18-0850>.