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CULTURAL AND SPIRITUAL APPROACHES TO INFANT DEATH IN PALLIATIVE CARE: A SYSTEMATIC REVIEW

María Elena CUARTERO-CASTAÑER, Maria FERRER-RIBOT, Virginia MORCILLO, Sebastià VERGER

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Cultural and Spiritual Approaches to Infant Death in Palliative Care: A Systematic Review

María Elena CUARTERO-CASTAÑER[1], Maria FERRER-RIBOT[2], Virginia MORCILLO[3], Sebastià VERGER[4]

Abstract

Supporting families coping with the loss of a child is a challenge in an increasingly culturally diverse world. This systematic review, conducted using the PRISMA methodology and covering the period from 2018 to 2022, analyzed 30 articles identified in Web of Science and Scopus to examine how cultural and spiritual beliefs shape the experience of pediatric palliative care. The results were organised into three thematic blocks: Islamic culture, Asian culture and a general category on cultural influence. In Islamic culture, acceptance of death as divine will and religious rituals offer comfort and meaning, although they can create tensions with clinical practice. In the Asian context, the centrality of the family, familism and rituals play a crucial role, although taboos surrounding infant death persist. In the general category, the difficulties faced by professionals in integrating the spiritual and cultural dimensions are evident, highlighting the need for specific training to provide culturally competent care. Across the board, the findings confirm that spirituality acts as a protective factor, although a lack of sensitivity to family beliefs can increase suffering. The conclusion is that there is a need to expand research to underrepresented cultural contexts and to develop guidelines to assist professionals in providing comprehensive and compassionate care for children and adolescents in palliative care.

Keywords: culture; spirituality; pediatric palliative care; death.

[1] Department of Philosophy and Social Work, University of the Balearic Islands, Balearic Islands, SPAIN. ORCID: https://orcid.org/0000-0002-9510-8721, E-mail: me.cuartero@uib.es

[2] Department of Applied Pedagogy and Psychology of Education, University of the Balearic Islands, Balearic Islands, SPAIN. ORCID: https://orcid.org/0000-0002-0448-8870, E-mail: maria.ferrer-ribot@uib.es

[3] Department of Applied Pedagogy and Psychology of Education, University of the Balearic Islands, Balearic Islands, SPAIN. ORCID: https://orcid.org/0000-0003-4417-6262, E-mail: virginia.morcillo@uib.es

[4] Department of Applied Pedagogy and Psychology of Education, University of the Balearic Islands, Balearic Islands, SPAIN. ORCID: https://orcid.org/0000-0002-4627-2082, E-mail: s.verger@uib.es

Introduction

The end of life is one of the most significant moments of human existence, as it brings to the fore the individual's spirituality and deeply rooted beliefs (Associació UNESCO per al Diàleg Interreligiós, 2015). These experiences are closely linked to culture, which plays a decisive role in shaping how each person perceives and copes with death (García-Navarro *et al*., 2010). In cross-cultural contexts, spirituality is recognised as a key resource for facing loss, providing emotional support and meaning in a highly complex process (Fiallos Quintero, 2019).

Culture, understood as the set of spiritual, material and symbolic elements that shape the identity of a community (UNESCO, 2012), is expressed through rituals and funeral practices that reflect shared beliefs and show that death transcends the individual to become a collective phenomenon (Mazzetti Latini, 2022). Understanding these beliefs and rituals is crucial for providing sensitive and meaningful care in situations of serious illness or loss (Mazzetti Latini & Vanadia, 2019).

Cultural perceptions of death are diverse, ranging from considering it the mere end of life to understanding it as a milestone in the spiritual journey or as a transition to an unknown destination. This plurality translates into varied approaches to how death is experienced and how life is understood about it (De Castro, 2017). Numerous studies highlight that spiritual beliefs play an essential role in constructing meaning in times of grief, influencing families' medical decisions (Benito, Dones & Babero, 2016; Mangione, Lyons & DiCello, 2016). Spirituality has also been identified as a protective factor against psychological stress, promoting acceptance of illness, difficult decision-making and strengthening coping (Koenig, VanderWeele & Peteer, 2024; Superdock, Barfield, Brandon & Docherty, 2018).

Religion can also influence treatment preferences and acceptance of certain interventions (Martin & Barkley, 2016). While it can offer support in times of crisis, it can also lead to conflict and spiritual distress when beliefs are challenged by life circumstances or clinical recommendations (Pargament & Exline, 2022). Sometimes, loss leads to a re-evaluation of faith that can result in profound transformations or even a loss of spiritual confidence (Wortmann & Park, 2009).

Given this diversity, professionals must understand and respect the cultural beliefs and practices of families, promoting open communication and offering personalised care that is tailored to their values and needs. Only in this way is it possible to guarantee compassionate and culturally sensitive support at the end of childhood and adolescence.

In this context, it is necessary to explore how different cultures and spiritual traditions influence paediatric palliative care and the experience of death during childhood and adolescence. This study aims to provide a broad overview that will enable an understanding of these dynamics and their implications for a more comprehensive and compassionate professional practice.

Aims of the review

Addressing death in childhood and adolescence entails a particular complexity, both due to the sensitivity of the process and the profound impact it generates on families, who often experience it with pain and uncertainty (Schonfeld, Demaria & Committee on psychosocial aspects of child and family health, disaster preparedness advisory council, 2016). Moreover, in many cultures, death continues to be a taboo subject, which hinders its management and the expression of spiritual needs related to this process (Ramos-Pla, Gairín & Camats, 2018). From this perspective, the present study aims to analyse how cultural and spiritual beliefs regarding childhood and adolescent death are manifested and articulated in the field of paediatric palliative care, based on a systematic review of the existing literature.

Methodology

The review was conducted following the PRISMA guidelines, which provide a standardised framework for ensuring transparency and rigour in systematic reviews (Page *et al*., 2021). The selection process included identification, screening, eligibility and final inclusion of studies, as illustrated in Figure 1.

Search Strategy

Two major databases were selected according to the subject area: Web of Science (WoS) and Scopus. The search period was restricted to 2018–2022, as intercultural and spiritual approaches to paediatric palliative care have evolved significantly in recent years, particularly in response to social, health and cultural changes that have reshaped care practices. The objective was therefore to capture the most recent studies reflecting current professional perspectives and concerns.

The search was conducted in March 2023 by two independent reviewers. Boolean operators (“AND”, “OR”) were used to combine and refine concepts, while specific descriptors were selected to narrow down results and ensure relevance. Table 1 presents the initial search results.

Table 1. Document search criteria

Databases	Search equation	N
WoS	("Culture" OR "Transcultural" OR "Spiritual" OR "Ethnic" OR "Custom" OR "Religion") AND ("End-of-life" OR "Palliative Care" OR "Death" OR "Dying") AND ("Children" OR "Pediatric")	778
Scopus	("Culture" OR "Transcultural" OR "Spiritual" OR "Ethnic" OR "Custom" OR "Religion") AND ("End-of-life" OR "Palliative Care" OR "Death" OR "Dying") AND ("Children" OR "Pediatric")	32
Total		810

To guarantee the quality and relevance of the studies included, the following inclusion criteria were applied: (a) original articles published in peer-reviewed scientific journals, (b) written in English or Spanish, and (c) published between 2018 and 2022. This ensured that the review focused on recent, high-quality research aligned with the study's objectives.

The exclusion criteria were: (a) articles published before 2018, (b) books, book chapters, conference proceedings or other non-peer-reviewed documents, (c) grey literature and preprints, and (d) studies focused exclusively on highly specific ethnic groups or with limited relevance to the paediatric field. These restrictions were designed to enhance methodological rigour, guarantee the applicability of results, and reduce potential bias from non-standardised or low-visibility sources.

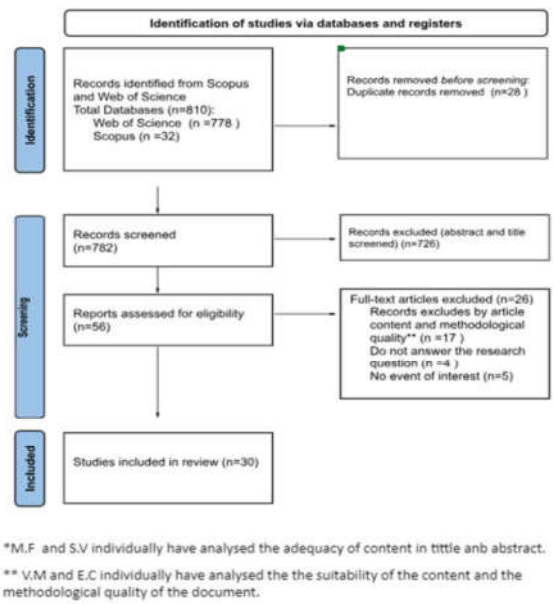

Figure 1. PRISMA flow diagram of the selection process

The PRISMA diagram (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) illustrates the process of identifying, screening and selecting the studies included in this review.

A total of 810 records were initially retrieved (778 from WoS and 32 from Scopus). After removing 28 duplicates, 782 articles remained for screening. Based on titles and abstracts, 735 records were excluded as irrelevant to the research objectives.

The 47 articles that met the initial criteria were assessed in full text. Of these, 17 studies were excluded: some for not meeting the established methodological quality standards, and others for not fully aligning with the scope of the study.

Finally, 30 articles m*et al*l the inclusion criteria and were incorporated into the systematic review.

Data extraction and quality assessment

A comprehensive summary table was developed to compile the main characteristics of the selected studies. This information is included in the Appendix (Table A1), where it is presented in a structured manner to facilitate comparison across the analysed documents.

The analysis of the included studies shows that all of them (100%) were published in English. The distribution by year highlights 2020 as the most frequent (33.3%), followed by 2018 (23.3%), 2019 and 2021 (16.6% each), and finally 2022 (10%). Concerning methodological approaches, qualitative studies predominated (63.3%), followed by quantitative (33.3%) and mixed-method designs (3.4%).

The quality appraisal was adapted to the methodological design of each study. Among the qualitative articles (n = 18), assessed using the *JBI Critical Appraisal Checklist*, 16 met at least 80% of the criteria, showing solid methodological consistency, transparent data analysis, and adequate ethical consideration, although most did not explicitly address researcher reflexivity. For the quantitative articles (n = 10), assessed with the *McMaster Critical Review Form*, eight achieved positive evaluations in more than 90% of the items, presenting clear objectives, coherent designs and appropriate statistical analyses. Nonetheless, several studies did not report the validity and reliability of their instruments in detail or justify their sampling procedures.

All studies were independently assessed by two reviewers, achieving a high level of agreement. Discrepancies were resolved by discussion and consensus. Regarding the two mixed-method articles, although no specific appraisal tool was applied, they were reviewed by two additional researchers following general criteria of methodological consistency and design quality.

Results

The presentation of the results is organised around three thematic blocks defined based on the predominant cultural approach in the studies reviewed: (1) Islamic culture, (2) Asian culture, and (3) a general category focusing on cultural influence in paediatric palliative care.

Table 2. Document characteristics

Authors	Title	Year	Topic
Akaberian *et al*.	Spiritual needs of mothers having children with cancer: A qualitative study.	2021	Spirituality Islamic
Arutyunyan *et al*.	Religion and Spiritual Care in Paediatric Intensive Care Unit: Parental Attitudes Regarding Physician Spiritual and Religious Inquiry	2018	Religion and Spirituality
Ben Taher *et al*.	Acceptability of post-mortem imaging among Muslim and non-Muslim communities.	2018	Islamic
Blossier & Rizzi	Talking about death with young children.	2020	Death
Bozkurt *et al*.	Relationship Between Coping Strategies, Religious Attitude, and Optimism of Mothers of Children With Cancer	2019	Religion
Broden *et al*.	Defining a “good death” in the paediatric intensive care unit	2020	Palliative care
Cai *et al*.	Spiritual needs and communicating about death in nonreligious theistic families in paediatric palliative care: A qualitative study	2020	Religion
Das *et al*.	Perceptions of family, community and religious leaders and acceptability for minimal invasive tissue sampling to identify the cause of death in under-five deaths and stillbirths in North India: a qualitative study	2021	Multicultural
Falkenburg *et al*.	The fragile spirituality of parents whose children died in the paediatric intensive care unit	2020	Spirituality
Gradick *et al*.	‘I’m praying for a miracle’: characteristics of spiritual statements in paediatric intensive care unit care conferences	2022	Spirituality

Hernandez	Family-Centred Culture Care: Touched by an Angel.	2019	Indú
Jung & Lee	Death of a child, religion, and mental health in later life	2022	Religion
Lewis *et al*.	"We might get a lot more families who will agree": Muslim and Jewish perspectives on less invasive perinatal and paediatric autopsy	2018	Islamic and Jewish
Lin & Huang	Consulting with a folk deity before making decisions: spiritual practices in parents facing end-of-life decisions for their child on life support with brain stem dysfunction.	2020	Spirituality
Liu *et al*.	A Descriptive and Phenomenological Exploration of the Spiritual Needs of Chinese Children Hospitalised with Cancer	2022	Spirituality
Livingston *et al*.	Shared spiritual beliefs between adolescents with cancer and their families	2020	Multicultural
Lyon *et al*.	Health Disparities: Barriers to Building Evidence for Effective Palliative End-of-Life Care for Spanish-Speaking Teens With Cancer	2021	Palliative care
Mack *et al*.	Racial and Ethnic Differences in Communication and Care for Children With Advanced Cancer.	2020	Culture
Parkinson *et al*.	How do health professionals provide spiritual care to seriously ill children?	2020	Spirituality
Rosenberg *et al*.	Pediatric Palliative Care in the Multicultural Context: Findings From a Workshop Conference	2019	Multicultural
Shi *et al*.	Culture-related grief beliefs of Chinese Shidu parents: Development and psychometric properties of a new scale	2019	Asian
Shields *et al*.	Religious Characteristics and Response to Legal Action Against Parents Who Choose Faith Healing Practices for Their Children	2018	Religion
Superdock *et al*.	Exploring the vagueness of Religion & Spirituality in complex pediatric decision making: a qualitative study.	2018	Religion and Spirituality

Tseng *et al*.	The meaning of rituals after a stillbirth: A qualitative study of mothers with a stillborn baby.	2018	Ritual
Wang *et al*.	Perspectives of Chinese Cancer Patients Toward Disclosure of Cancer Diagnosis to Their Minor Children	2020	Asian
Yu *et al*.	Exploring the lived experience of older Chinese "Shidu" parents who lost their only child: A phenomenology study	2020	Asian
Zajac & Boyatzis	Mothers' Perceptions of the Role of Religion in Parent-Child Communication About a Death in the Family	2021	Religion
Zambusi *et al*.	Physicians' knowledge about patients' religious beliefs in paediatric care.	2019	Religion
Zhang & Jia	A Qualitative Study on the Grief of People Who Lose Their Only Child: From the Perspective of Familism Culture.	2018	Culture
Zheng & Wuest	Assessing the impact of factors on parental grief among older Chinese parents.	2021	Asian

Islamic Culture

Islam offers a comprehensive view of life and death, guiding believers to face suffering with resilience, humility, and gratitude, understanding both processes as part of a divine plan. This perspective, centred on acceptance and spiritual meaning, converges with the principles of palliative care, which seek to provide relief, comfort, and quality of life. Thus, Islamic theology provides an ethical and spiritual framework that complements and enriches medical and psychosocial approaches to end-of-life care.

The article by Lewis *et al*. (2018) mentions that the Muslim religion prohibits traditional autopsies, as it is believed that the body should be buried as soon as possible and should not be disturbed unnecessarily. The Muslim religion has specific rituals surrounding death, such as washing the body and funeral prayers, which are important to the Muslim community. In addition, it seeks to identify cultural and religious barriers that may prevent families from accepting autopsies and how these barriers can be addressed to improve the autopsy acceptance rate.

Along the same lines, the study by Ben Taher, Pearson, Cohen & Offiah (2018) points out that people who practise Islam emphasise the importance of preserving the dignity of the body before and after death, following the teachings of Allah.

Islam advocates respect for the body and discourages the disfigurement of the corpse, as well as requiring early burial and prohibiting cremation. However, an Islamic fatwa issued in 1982 considers that the benefits of autopsy may outweigh its disadvantages, provided that it serves justice. Autopsy is a common practice in many countries to determine the cause of death, but it can conflict with religious beliefs, especially among Muslims, who prefer early burial.

The article by Akaberian, Momennasab, Yektatalab & Soltanian (2021) highlights several representative ideas related to the spiritual needs of mothers of children with cancer and the role of religion and spirituality in coping with this difficult situation. It was found that mothers experience significant spiritual needs that influence their emotional and physical well-being. Religion and spirituality become an important way of coping with the experience of having a child with cancer, providing emotional comfort, meaning and significance to the situation.

Asian Culture

The review confirms that Asian culture is diverse and complex, and that attitudes towards death in childhood vary significantly according to religious traditions, family values and social context. However, common elements are identified, such as the centrality of family and community, and the importance of rituals in the grieving process.

The study by Lin & Huang (2020), conducted in Taiwan, proposes a culturally adapted model of care that incorporates the voice of spiritual mediums from popular religions, highlighting how the spiritual practices of parents in life-sustaining situations help them cope with stress and find support in their faith. Along these lines, the authors point out that the lower acceptance of the concept of brain death among Asian families, linked to religious and cultural factors, can lead to conflicts with healthcare professionals.

In China, Liu *et al*. (2022) identified four core spiritual needs in children hospitalised with cancer: self-exploration, hope and inner peace, connection with others, and seeking support from gods, supernatural forces or even fictional characters. Hope was highlighted as a key motivating factor for continuing treatment, leading to recommendations for culturally specific interventions to improve the spiritual well-being of children. Other studies reinforce the importance of rituals. Tseng, Hsu, Hsieh & Cheng (2018) show how ceremonies allow mothers to maintain a bond with their deceased children, alleviate guilt and sustain hope for a future pregnancy. Complementarily, Zhou *et al*. (2019) and Zheng & Wuest (2021) agree that religion and culture directly influence the choice of spiritual practices and the interpretation of grief.

Beliefs in reincarnation, common in several Asian traditions, also offer comfort to families by framing death as part of the life cycle (Shi *et al*., 2019; Wang, Arber, Shen & Qiang, 2020; Yu, Lenny, Yu, Zheng & Liu, 2020). In particular, studies by Yu *et al*. (2020) and Shi *et al*. (2019) delve into the situation of Shidu parents,

those who have lost their only child. These studies highlight how familism and social expectations intensify grief and hinder the recovery process, as well as proposing tools for assessing culture-specific grief cognitions.

On the other hand, Zhang & Jia (2018) analysed the impact of familism on the grief and mental health of parents who lost their only child, revealing prolonged suffering related to social pressure to maintain the family lineage. Similarly, Yu *et al*. (2020) and Shi *et al*. (2019) describe how these cultural beliefs condition grief cognitions and can hinder emotional recovery.

Finally, some studies highlight the taboo surrounding infant death in certain communities. In Taiwan, for example, talking about death is socially restricted, limiting public mourning in cases of stillbirths, which are often made invisible (Tseng *et al*., 2018).

Cultural influence in the context of pediatric palliative care for children and adolescents

Studies addressing the cultural and spiritual dimension agree on the need for pediatric palliative care that recognises the diversity of beliefs and promotes respectful communication with families. Arutyunyan, Odetola, Swieringa & Niedner (2018) show the variability in parental attitudes toward spirituality in the Paediatric Intensive Care Unit, underscoring the importance of professional sensitivity. Along the same lines, Hernández (2019) highlights the value of culturally family-centred care, exemplified in the accompaniment of a Hindu family.

The influence of race and ethnicity has also been studied. Mack *et al*. (2020) point to inequalities in communication, decision-making, and access to services, which particularly affect minorities. Superdock *et al*. (2018) add that many professionals lack preparation to address spiritual issues or conflicts between family beliefs and medical recommendations. In turn, Shields, Miller, & Yelderman (2018) show how religiosity influences social responses when families reject medical treatment in favour of faith healing.

Several studies emphasise spirituality as a coping resource. Bozkurt, Inal, Yantiri, & Alparslan (2019) observe that greater religiosity in mothers of children with cancer is associated with increased optimism and social support, while Cai *et al*. (2020) reveal the complexity of discussing death in non-religious theistic families. Likewise, Das *et al*. (2021) and Broden, Deatrick, Ulrich & Curley (2020) underline that spiritual care is essential regardless of religious affiliation. In the same vein, Gradick, October, Pascoe, Fleming & Moore (2022) highlight its usefulness in coping with pain, and Falkenburg, van Dijk, Tibboel, & Ganzevoort (2020) stress its ability to provide comfort, hope, and meaning even in contexts of fragmented spirituality. Jung & Lee (2022) further point to its protective role against depression and anxiety after the loss of a child.

In adolescence, Livingston *et al*. (2020) confirm the relevance of spirituality in cancer care and advance care planning, while Zajac & Boyatzis (2021) show how maternal beliefs shape conversations about death, supporting coping with grief through faith and hope.

Finally, several studies highlight the training needs of professionals. Parkinson, Bray & Kool (2020) call for a clearer definition of spiritual care, training in cultural and religious sensitivity, and support in facing compassion fatigue. Rosenberg *et al*. (2020) and Lyon, Arem & Jacobs (2021) warn that lack of knowledge of cultural practices may create barriers, suggesting improved intercultural communication and collaboration with community and religious leaders. Along these lines, Zambusi, Cunha Di Sarno & Junqueira Alves (2019) reveal that, although paediatricians and residents consider themselves capable of addressing spirituality, attention to patients' religious identities is limited and overall preparation remains insufficient.

Discussion and conclusions

Culture and spirituality are essential dimensions in how families cope with death during childhood and adolescence. Far from being secondary aspects, these elements influence the experience of grief, clinical decisions and the relationship established with paediatric palliative care teams. In the case of Islamic culture, the studies reviewed show how religious principles structure both medical practices and rituals surrounding the end of life. The acceptance of death as divine will and the importance of preserving the dignity of the patient through specific rituals, such as washing the body and funeral prayers, become pillars for families (Akaberian *et al*., 2021; Ben Taher *et al*., 2018). This perspective offers a framework of comfort and meaning, while reinforcing shared values such as compassionate treatment and the alleviation of human suffering (Al-Shahri, 2016). However, the strict application of certain precepts can create tensions with clinical practice, especially regarding the use of certain medical interventions.

To Asian culture, the results highlight the centrality of family and community as fundamental pillars of coping. Traditions linked to Confucianism, Buddhism and familism emphasise the continuity of lineage, respect for ancestors and the value of rituals as elements of cohesion and comfort (Lin & Huang, 2020; Liu *et al*., 2022). Research with Shidu parents in China (Shi *et al*., 2019; Yu *et al*., 2020) highlights how cultural expectations can intensify suffering after the loss of an only child, showing that spirituality can function both as a source of support and a source of greater distress, depending on the context (Wortmann & Park, 2009).

The overall cultural influence reinforces the importance of incorporating a multicultural approach into paediatric palliative care. Several studies show that families value having their beliefs taken into account, although many professionals report limitations in effectively integrating the spiritual and cultural dimensions into their practice (Superdock *et al*., 2018; Falkenburg *et al*., 2020; Rosenberg *et*

al., 2019). This shortcoming has an impact on the quality of care and highlights the need for specific training to enable teams to provide culturally competent and sensitive care (Pargament & Exline, 2022).

Across the board, rituals and spiritual practices appear to be fundamental resources for coping, as they provide comfort, hope and a sense of n contexts of great vulnerability (Çaksen, 2021; Koenig *et al*., 2024). At the same time, a lack of sensitivity towards these aspects can generate conflict and increase suffering, especially when family beliefs come into tension with medical criteria. Hence the importance of promoting spaces for respectful dialogue that facilitate consensus-building between families and professionals and foster comprehensive and compassionate support.

Despite these advances, recent literature focuses on Islamic and Asian cultures, with no specific studies identifying other cultural realities such as Japanese, African, Latin American, Western or Russian. This absence limits the global understanding of the experience of death in childhood and adolescence and poses the challenge of broadening the perspective to more diverse contexts. Exploring these realities from educational and social perspectives, in addition to the medical perspective, would enrich the approach and enable the design of culturally sensitive guidelines to guide professionals from different fields in caring for families and patients in end-of-life situations.

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Institutional Review Board Statement

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