Spiritual assessment and spiritual care offerings as a standard of care in pediatric oncology: A recommendation informed by a systematic review of the literature

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Abstract
Children with cancer and their families experience shifts in spiritual wellness from diagnosis through treatment and survivorship or bereavement. An interdisciplinary team conducted a systematic review of quantitative and qualitative research on spiritual assessments, interventions, and outcomes in childhood cancer following PRISMA guidelines using a PROSPERO registered protocol. Thirty-nine well-designed studies were included in the final analysis. The findings from this systematic review indicate the need for early spiritual assessment with offering of continued support for the spiritual functioning of children with cancer and their families as a standard of care.

KEYWORDS
chaplain, palliative, pediatric oncology, pediatric, spiritual, spirituality

1 | INTRODUCTION

Children with cancer and their families benefit from interdisciplinary health care that includes spiritual or existential care domains.1–5 Spiritual care involves the exploration of illness, suffering, anticipatory grief, chronic and terminal conditions, and losses as well as the search for justice, purpose, hope, resiliency, relationships, meaning, and life legacy.6–9 The longitudinal scope of existential care may help alleviate spiritual suffering and distress for children with cancer and their families and may lead to postures of empowerment, growth, and resiliency.10–13

In 2015, a Special Edition of Pediatric Blood and Cancer featured 15 comprehensive, implementable standards for pediatric psychosocial care based on research evidence and best clinical practice.14 The Psychosocial Standards of Care Project for Childhood Cancer championed an interdisciplinary stakeholder process to develop consensus-based, academically informed, and clinically relevant standards for pediatric psychosocial care in childhood oncology.14 The present study built upon the previously published Standards of Psychosocial Care, as spirituality was recognized in the Standards as instrumental in contributing to the well-being of children with cancer and their families during treatment15 and through bereavement.16 The Standards recognized the role of spiritual leaders as psychosocial and intervention support partners for children and families.17 The Standards recognized that pediatric and adolescent oncology patients and their family members may obtain social connectedness through their faith communities.18
The Standards emphasized the importance of assessing “cultural and spiritual beliefs and practices in the context of the family’s and patient’s reactions to illness and treatment.” Only one published Standard used search terms “spirit” or “faith,” and thus there was recognized opportunity to target an exploratory search on “the impact of spirituality and spiritual services” on psychosocial outcomes.

Integrating spirituality, faith, and religious beliefs into the plan of care is becoming an identified practice model in pediatrics. The World Health Organization acknowledges that holistic care that integrates the role of faith, existential questioning, and meaning in care benefits patients and their families. Some patients and families identify that religious and spiritual beliefs support and sustain meaning and that health provider inclusion of spirituality enhances their care. The specific ways spirituality may impact a child or a family’s experience with cancer diagnosis, prognosis, and treatment remains a gap in the current knowledge base, as does a summary of spirituality interventions and outcomes for children with cancer and their families. To expand the scope of the previously published Standards of Psychosocial Care in pediatric oncology, we performed a systematic review to quantify and qualitatively assess the practice of spiritual care in pediatric cancer.

2 METHODS

This systematic review followed the methodology of the Standards of Psychosocial Care. An interdisciplinary team of experts in oncology, palliative care, psychology, nursing, social work, spiritual care, and library science from diverse geographies was established. Monthly conference calls were conducted between May 2018 and March 2019.

The PRISMA (preferred reporting items system meta-analysis) systematic review guidelines were utilized for methodology and reporting with the systematic review protocol registered with PROSPERO as CRD42019121634.28,29 Reviews and descriptive/correlate, qualitative, and quantitative studies (randomized controlled trials, prospective nonrandomized pre-/posttest, wait-list control) published in peer-reviewed journals were included. Editorial, position papers, case studies, commentaries, expert reports, abstracts, and dissertations were excluded. Study populations included pediatric, adolescent, and young adult cancer patients (birth to age 40 years) as well as their caregivers and siblings.

A medical librarian (RSH) conducted a systematic search of the literature. Exact search terms are given in Supporting Information S1. Ovid-Medline, Ovid-Embase, PsychInfo, and Cochrane Library databases were queried using both natural language and controlled vocabulary terms for Religion, Spirituality, Prayer, Malignancies, Pediatrics, Children, and Families. Each database was queried on March 5, 2018, and the results were limited to English-language articles published from 2007 to 2018.

The initial search generated 626 citations. Two reviewers (RR and KP) independently screened the citations by title and abstract for eligibility, eliminating 519 citations. The reviewers agreed on all determinations. Of the remaining 107 citations, 68 were determined to be ineligible, leaving 39 eligible articles. Each eligible article was reviewed by two experts blinded to the data extraction process of the other reviewer, and consensus agreement was established by a third-party review for 12 articles. The PRISMA flow diagram is given in Figure 1.

The Mixed-Methods Appraisal Tool version 2011 was applied to all eligible studies. This 27-item checklist, designed and validated for systematic reviews, allowed for concomitantly appraising qualitative, quantitative, and mixed-methods studies. Predefined data extraction fields, including study quality indicators, were designed by the first (RR) and last (MW) authors. Three reviewers piloted the data extraction sheet, with each reviewer conducting five pilot reviews before a final version of the data extraction sheet was drafted. The data extraction sheet captured study details such as study design, location, and length; the population of interest, including age and diversity; the study’s population of interest, including sample size; the definition of spirituality according to the study captured in exact quotations from each paper; study objectives; and findings including statistical significant differences and qualitative summaries. The data extraction sheet also captured domains of spiritual care addressed by the study, including spirituality as a predictor of outcomes, spiritual care needs assessments, spiritual care service utilization, and spiritual care intervention efficacy. Funding sources, author recognition of bias, and study rigor were analyzed per article. Data extraction included a systematic approach to analyzing organizational barriers to implementation, tools or instruments used for spiritual assessment, and benefits, burdens, and/or harms mentioned in each article. The final evaluation of each article was based on Grading of Recommendations, Assessment Development, and Evaluation (GRADE) criteria to develop a summary of evidence (Table 1). GRADE, a quality method to rating the certainty of evidence in systematic reviews, was used in the prior Psychosocial Standards. GRADE offered a transparent framework to assess the quality of current evidence and to present the strength of the recommendation in this Standard. The Standard was endorsed by the International Society of Pediatric Oncology Palliative Care Working Group and the Association of Pediatric Oncology Social Workers.

3 RESULTS

3.1 Definitions of spirituality

The studies defined spirituality through eight emerging themes identified through content analysis of direct quotes defining spirituality from each paper completed by the study team chaplain (KL) and content-checked by the last author (MW): faith, meaning, religion, sense of the divine or a higher power, vitality and gratitude, spirituality, existential wellness, and hope. Seven studies defined spirituality in the context of faith, such as seeking healing, engaging in prayer, or participating in faith traditions. Spiritualit was defined as religion or religious coping and religious beliefs in five studies and as seeking a higher power or the divine in three studies. In three studies, posttraumatic
**TABLE 1** Summary of evidence—assessing spiritual needs in children and adolescents with cancer and their families

<table>
<thead>
<tr>
<th>Standard</th>
<th>Evidence summary</th>
<th>Methodology</th>
<th>Quality of evidence</th>
<th>Strength of recommendation</th>
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<tr>
<td>Youth with cancer and their family members should routinely receive systematic assessments of their spiritual care needs.</td>
<td>The diagnosis and treatment of childhood cancer has a significant impact on the spiritual and existential functioning of children and their families, including causing shifts in how children and families perceive meaning, hope, and relationships.</td>
<td>33 research studies(^b) and six systematic reviews.</td>
<td>Moderate quality of evidence given with consistent findings from numerous studies on the role of spiritual care assessments. Evidence gaps include prospective research on evidence-based or outcomes-measured spiritual care interventions.</td>
<td>Strong recommendation for spiritual needs assessments based on quality of observational evidence as well as the risk of existential crisis; decreased sense of meaning, justice, and/or hope; faith community isolation; and/or spiritual distress going undetected and unaddressed.</td>
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<td>Teams should consider spiritual care offerings congruent with family belief systems during and after treatment.</td>
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\(^a\) Based on the summary of evidence table for that standard.

\(^b\) Research studies included randomized controlled trials, cross-sectional studies, longitudinal studies, and consensus studies.

\(^c\) Quality of evidence was based on GRADE criteria.

\(^d\) Strength of recommendation was based on GRADE criteria.
growth, the development of new values, and clarity of life priorities were depicted as part of the spiritual process during pediatric cancer treatment.\textsuperscript{39,50,51} Wellness and personal reflection practices, such as yoga and mindfulness, were common forms of integrating one’s spirituality into daily life.\textsuperscript{52,53} Spirituality for the pediatric cancer patient and family was defined through wellness, positivity, coping, distress adaptation, and life beliefs.\textsuperscript{3,40,50,54,55} Spirituality definitions included transcendence of one’s experience and growth in and through suffering.\textsuperscript{39,41,56} The theme of spiritual hope was defined in the articles as “intentional hope” and “hope as inner strength.”\textsuperscript{42,57}

### 3.2 Study designs, settings, and participants

A comprehensive summary of population, methods, objectives, key findings, and level of evidence for all included articles is available as Supporting Information Material S2. Of the 39 articles included in final synthesis, six were review articles covering a mean of 21 articles (range, 9–37 articles).\textsuperscript{3,32,37,39,40,58} Review article topics included summaries of spirituality among oncology patients and families;\textsuperscript{3,40,58} quality of life or inner growth relevant to spirituality in pediatric oncology;\textsuperscript{32,39} and cultural and religious considerations in care.\textsuperscript{57}

Of the 32 research studies, three studies included experimental intervention with comparison arms.\textsuperscript{38,43,59} Ten were interview-based;\textsuperscript{8,35,45,48,50,54,56,57,60,61} 12 were observational studies;\textsuperscript{3,32,34,44,46,51,53,61–64} and seven were in questionnaire or written survey format.\textsuperscript{36,42,47,49,52,56,56} Most used one time-point, and only 6 (18%) used longitudinal time points, including at two months,\textsuperscript{38,43,59} three months,\textsuperscript{33} five months,\textsuperscript{56} and nine months.\textsuperscript{2} Contact settings included home-based settings;\textsuperscript{35,36,46,50,53,54,64,65} outpatient clinics,\textsuperscript{36,57,63} hospital-based settings,\textsuperscript{2,8,33,38,42–45,47,52,55,59–62,56,66} and multiple settings.\textsuperscript{41,56,63}

Twelve studies enrolled patients at multiple sites,\textsuperscript{2,3,5,41,46–48,50,55,57,61,63,64} whereas 21 enrolled patients at a single site.\textsuperscript{3,38,34,36,38,42–45,49,51–54,56,59,60,62,65,66} Study locations included the United States;\textsuperscript{8,34,35,41,44,46,48,49,51–54,56,59,60,62,63,64} Australia;\textsuperscript{47} Brazil;\textsuperscript{60} Canada;\textsuperscript{66} Finland;\textsuperscript{57} Germany;\textsuperscript{65} Iran;\textsuperscript{38,43,59} Israel;\textsuperscript{44,62,65} Lebanon;\textsuperscript{33} the Netherlands;\textsuperscript{36} Switzerland;\textsuperscript{50} and Turkey.\textsuperscript{55}

The spiritual preferences of patients were included in 24 studies;\textsuperscript{3,8,32,33,37,39,40,42,45,47–50,52,53,56–58,60,61,63–65} those of family members in 24 studies;\textsuperscript{2,3,33–37,39–47,49,51,52,54,55,58,59,66} and those of staff in two studies.\textsuperscript{3,58} The papers that elicited pediatric cancer patient perspective on their own spiritual care needs were primarily timed during the survivorship timeframe, as patients retrospectively described spirituality in the setting of survivorship.\textsuperscript{3,2,39,45,48,50,54,61,64,65} Child voice was included in the following formats: an open-ended interview on hope;\textsuperscript{57} spiritual quality-of-life interviews;\textsuperscript{56} needs assessment discrete choice exercise;\textsuperscript{47} interview responses about coping strategies during chemotherapy hospitalizations;\textsuperscript{50} or transplant,\textsuperscript{8} in association with advance care planning experience,\textsuperscript{67} and in integrative therapy use.\textsuperscript{52,53}

Among the studies that identified the participants’ religious affiliations, five studies had primarily Muslim populations;\textsuperscript{3,33,38,43,44,59,62} one had a predominantly Jewish population,\textsuperscript{32} and the remainder had primarily Christian populations. No study had a population whose participants primarily self-identified as Hindu, Buddhist, agnostic, or atheist. In addition to lacking religious diversity, the studies also lacked ethnic diversity. Most studies conducted in the United States had only small populations of African American participants,\textsuperscript{3,34,35,41,45,46,51,52,54,61,64} Native American participants,\textsuperscript{32,51,53} Latino participants,\textsuperscript{3,41,42,48,51,52,56,61,64} or Asian participants.\textsuperscript{51,42,46,51,52} Only one study specifically investigated the psychosocial/spiritual needs of families of culturally diverse backgrounds.\textsuperscript{42}

Study tools included depression and anxiety scales;\textsuperscript{38,43,45,65} burnout;\textsuperscript{59} or burden scales;\textsuperscript{34} trauma, posttraumatic stress or resiliency, or grief scales;\textsuperscript{36,51,54} relational scales;\textsuperscript{49,54} benefit or coping scales;\textsuperscript{54} symptom inventory, illness impact, or functional assessments;\textsuperscript{49,54,55,58} hope scales;\textsuperscript{32,61} and quality-of-life metrics.\textsuperscript{32,53,55,56} Spiritual scales used included Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale;\textsuperscript{52} Spirituality and Spiritual Care Rating Scale;\textsuperscript{32} Spiritual Quality-of-Life interview;\textsuperscript{56} Spiritual Well-Being Scale;\textsuperscript{53} Islamic Positive Religious Coping and the Punishing Allah Reappraisal-Subscales of the Psychological Measure of Islamic Religiousness;\textsuperscript{42} Complementary and Alternative Therapies Questionnaire;\textsuperscript{44} Religious Belief Questionnaire and Religious Behavior Questionnaire;\textsuperscript{65} Religious Commitment and Brief Multidimensional Measure of Religiousness/Spirituality Scale;\textsuperscript{58} Posttraumatic Growth Inventory-Spiritual Change Subscale;\textsuperscript{51} FICA Spiritual Assessment Tool;\textsuperscript{58} and Brief Measure of Religious Coping.\textsuperscript{54,58}

### 3.3 Interventions

Of the research studies, only three (10%), all from Iran, included an intervention. In one study, parents attended six weekly 45-minute educational-spiritual lectures followed by small-group discussions with a significant difference in parent burnout immediately after and again measured one month after intervention (\(P < 0.001\)).\textsuperscript{59} In another study, mothers attended seven group meetings for spiritual care training with significant differences in anxiety; in spiritual, religious, and personalized care perspectives; and in perception of spiritual care between the intervention and control groups at follow-up (\(P < 0.001\)).\textsuperscript{38} In another study, mothers attended six sessions of spiritual care with improved maternal mental health scores before and after intervention.\textsuperscript{42}

A summary of the domains of spiritual care by stakeholder, spiritual needs assessment, aspects of care, and spiritual care intervention is given in Table 2.

### 3.4 Perceptions of spirituality

In one study, parents of children with cancer gave higher value ratings to the involvement and availability of a spiritual mentor (\(P = 0.03\)) in their family’s care than clinician ratings of the role of a spiritual mentor for a family.\textsuperscript{66} In another study, some families received relational support through their spiritual or religious community.\textsuperscript{49} Spiritually supportive conversations were viewed as helpful\textsuperscript{8} or supportive\textsuperscript{33}
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<th>Study first author</th>
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<td>Spiritual care needs assessment</td>
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<td>Chaplain encounter</td>
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by family members of children with cancer in individual studies. Adolescents in a study noted that chaplain inclusion was supportive and helpful in translating beliefs and concerns to the oncology care team.\(^8\) Children indicated that their religion,\(^32,60\) particularly the role of ritual and prayer,\(^56\) helped them cope with treatment. Children perceived religious practices as helpful and a form of support, primarily in strengthening their hope for a cure in a study\(^60\) and fostering relatedness in another study.\(^56\) Parents endorsed spirituality as a resource for coping\(^2,3,6,51,54\) and utilized spiritual education with decreased burnout in another study.\(^59\) Spirituality was correlated with parental self-perceived mental health or subjective well-being.\(^38,43,44\) Parents also associated spirituality with helping them overcome fears in one study\(^46\) and find hope.\(^3,40,57\) Parents in another paper perceived positive religious coping as a predictor of life satisfaction.\(^44\) For parent caregivers in one study, peace of mind was highly relevant to communication and trust.\(^41\) Positive spiritual coping, optimism, and illness impact uniquely predicted overall benefit-finding for caregivers in one study of childhood cancer survivors.\(^54\)

One study conducted in Turkey investigated the correlation between parents’ spiritual perception and their child’s symptom burden.\(^55\) In that study, pediatric symptom frequency impacted parental perception of spirituality; as pediatric symptom frequency increased, parents’ life quality spiritual wellness subsdimension was negatively affected (\(P = 0.008\)).\(^55\) Another study conducted in Israel investigated the impact of spiritual association or religious affiliation on goals of care for parents of children with solid tumor diagnoses.\(^62\) This study revealed that the likelihood of providing do not resuscitate consent did not differ significantly among parents of Jewish, Islamic, and Christian background.\(^62\)

Bereaved families depicted the role for spirituality or ritual in offering comfort or tangible coping.\(^35,39\) One study showed bereaved parents’ faith was not associated with less long-term traumatic grief (odds ratio = 0.86, \(P = 0.51\)) or symptoms of depression (odds ratio = 0.95, \(P = 0.74\)).\(^36\) Spirituality was noted to be an evolving process, as 10% of bereaved family members (\(n = 99\)) noted themselves feeling closer to the divine, whereas 2% felt more spiritual distance.\(^46\)

Only two studies reported on potential burdens of spirituality. Burdens were depicted primarily as a parental perception of illness as a divine punishment or the perception of cancer as a consequence for human misdeeds/sins. Exemplary quotes of burden included: “For some participants, the appraisal of being punished by God might have…caused pain and distress”\(^44\) and “seeing illness as a punishment from God or for sins.”\(^3\)

Organizational barriers to spiritual assessment included difficulty in recruitment\(^48\) and difficulty in accrual retention due to participants’ physical illness.\(^56\) In seven articles, the authors mentioned and explained bias.\(^33,36,45,52,53,57,62\) No included paper depicted blinding either participant or researcher.

### 4 | DISCUSSION

The results of this systematic review indicate that the diagnosis and treatment of pediatric cancer significantly impact children and caregivers in terms of concepts commonly associated with spirituality. However, the evidence is not sufficiently robust to indicate preferred interventions and approaches to supporting children and families. There is a distinct lack of intervention studies or outcomes reporting. Indeed, one of the biggest challenges to conducting and summarizing this review was the lack of a standard definition of spirituality and the diversity of possible interpretations of these concepts. In general, studies tended to conclude that spiritual support is perceived by patients and caregivers as supportive and helpful, and evidence for spirituality as a resource for coping was strong. Spiritual support for bereaved families was related to comfort and coping, and spirituality was associated with meaning-making and hope for both children and parents. This review’s findings emphasize the importance of spiritual needs assessment to all children and families, as well as ongoing
offering of spiritual care congruent with patient and family belief systems throughout treatment and survivorship.

The methodological strengths of our review included its inclusion of studies that used a wide range of scales and tools to assess facets of spirituality, with many studies using structured tools applicable to future research and potential clinical adaptation. Many of the studies’ authors employed creative methods to include the patient’s perspective; in one study, for example, a puppet created by the child was used as a vehicle for developmentally informed inquiry to capture the child’s voice.60

Our systematic review highlights several gaps and limitations in the literature, pointing to a number of areas suitable for future research. Overall, the studies included in this review lacked coherence in terms of theoretical models and definitions of spirituality, which can include hope, faith, religion, support, and meaning-making, among other concepts. There was also a noticeable lack of exploration of the association between spirituality and outcomes such as healthcare utilization, cost-effectiveness or resource allocation, symptom control, physiological impact, or medical adherence. In addition, spiritual interventions were generally lacking in this review, and the small number of intervention studies limits the body of evidence from which to derive recommendations. However, three studies from Iran showed evidence for spiritual intervention efficacy on parental variables, including maternal mental health and feelings of parental burnout.38,43,59 The implications of these three studies are meaningful for the potential role of spiritual assessment and intervention for self-care, community connectedness, or resiliency outcomes.

The findings of studies included in this review did not universally endorse a preference for spiritual support, thus highlighting the need for spiritual needs assessment as essential to linking preferred support and available spiritual care resources. For example, one Australian study indicated that adolescent and young adult patients and their caregivers were indifferent toward spiritual support but had a clear preference for support for patient and family emotional functioning, support for financial needs, and support for return to school and work.67 However, the authors of that study noted the significant heterogeneity in their data, suggesting that a portion of their sample indeed valued spiritual support even though group findings were not significant. This highlights the importance of giving patients and their families the opportunity to identify spiritual needs to ensure congruence with spiritual beliefs and to appropriately align interventions. It also reinforces the need to have clear conceptual definitions of spirituality, as some of the more valued supports could be included in a holistic spiritual conceptual framework.

Finally, the reviewed studies gave little attention to the potential burdens associated with spirituality, yet these may be highly relevant to the development of spiritual needs assessments and interventions. For example, distress stemming from the attribution of illness to divine punishment, as reported in two studies,3,44 may be a worthy target for spiritual support.

One potential limitation of this review was the lack of a longitudinal design among studies. The experience of pediatric cancer is individual and not static, as patients and families must navigate changes in clinical status, diagnostic formulation and treatment, and even prognosis. Like the cancer experience, cultural traditions and the influence of religion and meaning-making are dynamic factors that may shape the way in which spiritual needs change over time and the way in which spiritual support shifts in concert with cancer-related variables and experiences.67 Another potential limitation was the lack of ethnic and religious diversity within study populations (e.g., a lack of or limited inclusion of Jewish, Hindu, and Buddhist participants), which may have been related to the English-language search limitation. Lack of diversity impedes the generalizability of our findings across cultural and religious traditions. Further, the studies included in the review generally lacked participants who identified as atheist or agnostic or otherwise not spiritual in a religious sense. Recognizing the full range of cultural and religious diversity in many pediatric cancer settings is essential to developing appropriate spiritual needs assessment and clinical care.

5 CONCLUSION

Spirituality is an understudied and poorly defined construct in pediatric cancer care. Despite its inclusion of studies lacking rigorous interventions and a cohesive definition of spirituality, this review still underscores the importance of spiritual concepts and support for children and families facing cancer. Owing to the lack of diversity in the studies reviewed, clinicians should continue to utilize a personalized approach to identifying the spiritual needs of patients and their families. This review’s findings point to a need for individualized, culturally relevant assessment that encompasses a larger, holistic definition of spirituality. Logical next steps in research include the continued development of a conceptually clear construct of spirituality that includes hope and meaning-making and fewer traditional religious definitions as well as more intervention studies, more studies with diverse populations, and more studies targeting different and unique development groups such as adolescents and young adults. Overall, this review revealed that spiritual assessment should be offered in pediatric oncology as a psychosocial standard of care but that caution should be taken to ensure that children, adolescents, and families receive tailored and appropriate support that meets their individual cultural and spiritual needs.

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CONFLICTS OF INTEREST

The authors report no known conflicts of interest.

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**SUPPORTING INFORMATION**

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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