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# Matters of Spirituality at the End of Life in the Pediatric Intensive Care Unit

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## ABSTRACT

**OBJECTIVE.** Our objective with this study was to identify the nature and the role of spirituality from the parents' perspective at the end of life in the PICU and to discern clinical implications.

**METHODS.** A qualitative study based on parental responses to open-ended questions on anonymous, self-administered questionnaires was conducted at 3 PICUs in Boston, Massachusetts. Fifty-six parents whose children had died in PICUs after the withdrawal of life-sustaining therapies participated.

**RESULTS.** Overall, spiritual/religious themes were included in the responses of 73% (41 of 56) of parents to questions about what had been most helpful to them and what advice they would offer to others at the end of life. Four explicitly spiritual/religious themes emerged: prayer, faith, access to and care from clergy, and belief in the transcendent quality of the parent-child relationship that endures beyond death. Parents also identified several implicitly spiritual/religious themes, including insight and wisdom; reliance on values; and virtues such as hope, trust, and love.

**CONCLUSIONS.** Many parents drew on and relied on their spirituality to guide them in end-of-life decision-making, to make meaning of the loss, and to sustain them emotionally. Despite the dominance of technology and medical discourse in the ICU, many parents experienced their child's end of life as a spiritual journey. Staff members, hospital chaplains, and community clergy are encouraged to be explicit in their hospitality to parents' spirituality and religious faith, to foster a culture of acceptance and integration of spiritual perspectives, and to work collaboratively to deliver spiritual care.

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### Key Words

spirituality, religion, end of life, parent, PICU, pediatric palliative care

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**T**HE VAST MAJORITY of the US population considers itself to be spiritual or religious, with 9 of 10 people believing in God or a higher power.<sup>1,2</sup> Among adults who face illness, this percentage increases to 95% who believe in God.<sup>3,4</sup> Patients and family members acknowledge their spirituality and religion as important in the face of illness and death, providing guidance with end-of-life decision-making, ascribing meaning to the loss, and offering emotional sustenance.<sup>2,5-8</sup> Parental religious and spiritual perspectives and resources can affect and influence parents' understanding of and approach to illness, disability, and end-of-life decision-making.<sup>5,9-12</sup> These findings are in keeping with the mounting evidence that patients and family members desire greater inquiry and integration of their spirituality from their health care practitioners, especially in times of grave illness.<sup>3,7,13-15</sup> Despite the dominance of technology and medical discourse in the pediatric intensive care setting, the end of a child's life and its aftermath can be experienced for many parents as a spiritual journey.<sup>12</sup>

The American Academy of Pediatrics recognizes the significance of spirituality as an integral aspect of good pediatric palliative care and views spiritual advisors as essential members of the pediatric palliative care team.<sup>16</sup> In addition, the current Joint Commission on Accreditation of Healthcare Organizations standards mandate the assessment of spiritual needs of the family of every child who receives end-of-life care and the availability of spiritual care providers to address these needs.<sup>17</sup> Some have questioned whether staff members are adequately prepared, willing, or able to discuss and incorporate spirituality into everyday clinical practice in the PICU.<sup>18</sup>

Contemporary medical literature does not provide consensus on definitions of religion and spirituality.<sup>19</sup> Religion may be considered a group's enculturation of an organized system of beliefs, texts, roles, and practices related to spirituality. Spirituality may be considered a personal search for meaning and purpose, and a trusting relationship to something that is greater than oneself and that is significantly meaningful. Spirituality is useful in the medical setting for its lens on identifying the variety of people and things that serve an individual as trustworthy and significantly meaningful spiritual resources.<sup>20</sup> This perspective allows care providers to help parents identify their own unique spiritual resources and then to support parents in drawing on them appropriately in times of crisis. Regardless of religious tradition, many parents draw on additional resources that may have spiritual meaning to them, such as family, friends, ethnicity, country, ideals, nature, the community of others who are suffering, and, in some cases, the health care team.

Studies that examined the spiritual beliefs and the needs of parents whose children are hospitalized and dying have concluded that the amount and the quality of spiritual care that is available to parents is insuffi-

cient.<sup>2,11,21-23</sup> A recent study reported that 60% to 80% of parents of hospitalized children had unmet spiritual needs.<sup>2</sup> The death of a child can precipitate intense spiritual distress among parents<sup>24,25</sup> and has been associated with increased risk for psychiatric illness and even mortality for parents.<sup>25-27</sup> This underscores the need to understand better the parents' spiritual experience of their child's death and to provide improved spiritual care. Provision of spiritual care is an important yet often overlooked aspect of holistic care, with roles for spiritual care generalists and specialists.<sup>5,13,14,28,29</sup>

Our previous work<sup>9,30</sup> demonstrated that faith is important and helpful to many parents who face the death of a child, in addition to honest information, ready access to staff, communication and care coordination, emotional expression and support by staff, and preservation of the integrity of the parent-child relationship. Parents reported that their spiritual/religious beliefs often were important to their coping efforts during their child's hospitalization and remained so after death. In addition, nearly one third of parents rated spiritual/religious beliefs as very important in the process of end-of-life decision-making. Parents identified community religious figures as vital and particularly available members of their social support network, serving parents in diverse and helpful ways during and after the child's death.

The purpose of this study was to examine the nature and the role of spirituality and religion at the end of life from the parents' perspective. The data were derived from open-ended, qualitative questions as part of a larger study that examined parental decision-making, social support, and priorities and recommendations for care at the end of life.<sup>9,30</sup> Here, we present parents' own words to understand better their needs, priorities, and suggestions related specifically to spirituality at the end of life and to discern useful clinical implications.

## METHODS

### Design

The present study was part of a larger 3-site study that administered parent self-report questionnaires to examine parental perspectives of end-of-life care in the PICU, including Children's Hospital Boston, Massachusetts General Hospital, and Tufts New England Hospital.<sup>9,30</sup> Using standard qualitative content analysis methods,<sup>31-34</sup> parental responses to open-ended questions were read and categorized into themes to describe the nature and the role of parental spirituality at the end of their child's life.

### Participants

Parents whose children had died in the ICU after the foregoing of life-sustaining treatment were eligible to participate. The deceased children ranged in age from

newborn to 18 years and represented the full range of pediatric medical and surgical diagnoses. Parents completed the questionnaires 12 to 45 months after their child's death.

### Questionnaire and Data Collection

The Parental Perspectives Questionnaire<sup>9</sup> was designed to elicit parental ratings about the end-of-life care and experience, adequacy of pain management, decision-making, and social support. In addition to Likert-style quantitative items, the survey included 5 open-ended questions that were the focus of the current qualitative analysis:

- What was most helpful to you in getting through the time at the end of your child's life?
- What was least helpful to you in getting through the time at the end of your child's life?
- How can the hospital staff improve their communication with parents at this difficult time?
- What advice do you have for hospital staff members in helping parents during this difficult time?
- What advice do you have for other parents who are facing a similar situation?

Although the questions did not ask explicitly about spirituality or religion, parents spontaneously offered spiritual/religious responses, suggesting the importance of these issues.<sup>30</sup> Here, we analyze and present in greater detail data about the nature and the role of parents' spirituality at the end of life in the PICU, including data about the advice that parents would offer to other parents under such circumstances.

### Data Analysis

Parents' written responses to the open-ended questions on the Parental Perspectives Questionnaire were read and the content was analyzed by the first 2 authors (M.R.R. and M.M.T.), who served as the primary coders and whose training is in pastoral care. Content analysis<sup>31-34</sup> was conducted through a process of reading and marking key words and phrases to identify topics and issues of importance to parents. The primary coders independently read and coded the responses; then, in face-to-face discussions, the spiritual and religious responses were grouped into themes and labeled accordingly. Agreement about thematic content and labeling occurred when the primary coders reached consensus through a process of rereading and discussion. Interrater agreement was acceptable at 83% between the primary coders and the secondary coder (M.M.B.). The overall frequency and the percentage of spiritual/religious responses were calculated on the basis of parental responses across all of the qualitative questions. Similarly, the frequencies and the percentages of both the explic-

itly and implicitly spiritual/religious responses were calculated and reported on the basis of responses across all of the qualitative questions.

### Research Ethics

The institutional review boards of the 3 participating hospitals approved the study design and Parental Perspectives Questionnaire. A cover letter and consent form accompanied each questionnaire to explain the purpose of the study, directions, and study methods designed to ensure confidentiality. Parents were instructed to read the informed consent and, if they wished to participate, to check a box indicating so on the questionnaire. Information that could identify the patient, parent, or institution was not solicited.

### RESULTS

Of 96 eligible households, we analyzed 56 (58%) questionnaires from 56 parents of 56 different children, including 36 (64%) mothers and 20 (36%) fathers. The mean age of parents who responded was 42.3 years ( $\pm 8.4$ ), and 75% were married. Ninety-one percent of the sample was white. Regarding religious affiliation, 50% identified themselves as Catholic, 34% as Protestant, 5% as Jewish, and 2% as Muslim, and 9% indicated no religious affiliation.

Overall, 73% (41 of 56) of parents offered spiritual/religious responses when asked what had been most helpful to them and what advice they would offer others at the end of life in at least 1 of the 5 open-ended questions on the survey. Sixty-one percent (34 of 56) of parents provided explicitly spiritual/religious responses, and 46% (26 of 56) provided responses that were implicitly spiritual in nature. The questions that yielded the most spiritual/religious responses were, "What was most helpful to you in getting through the time at the end of your child's life?" and, "What advice do you have for other parents who are facing a similar situation?" In general, responses that were intended for other parents were more spiritual/religious and personal in nature than those that were directed toward health care providers, with language that was more conversational and emotionally laden.

### Explicitly Spiritual/Religious Themes

Four explicitly spiritual/religious themes emerged: prayer, faith, access to and care from clergy, and belief in the transcendent quality of the parent-child relationship that endures beyond death. Representative quotations of each of these themes are presented below:

#### *Prayer*

When asked what was most helpful when coping during their child's final days, and what advice they might offer to other parents, several parents indicated prayer:

"We. . .prayed a tremendous amount."  
"Pray for strength."  
"Be strong and pray."  
"Pray and don't be afraid to ask the staff questions."  
"Pray!"

### *Faith*

Many parents identified their faith in God when asked what was most helpful to them at the end of their child's life and what they would suggest to other parents who were facing similar situations:

"My faith and knowing that my child had the same faith."

"My faith and trust in God who was in charge of Jessie. Knowing she would not suffer no more when she went home to be with the Lord."

"The people God provided for us along the journey, friends, family, doctors, nurses, clergy."

"Put your faith in God."

"Trust in God."

A notable exception was 1 mother who listed faith as least helpful to her during the end-of-life experience:

"Just when I needed my faith, I hated it, for deceiving both my child and myself!"

### *Access to and Care From Clergy*

Several parents identified the importance of ready access to both their own familiar community clergy person and the hospital chaplain:

"The services of my rabbi [were most helpful]."

"Allowing our minister. . .to have access to us."

". . .a discussion with our pastor confirming we had the scriptural authority to make these decisions [withdrawal of life-sustaining therapies] was very helpful."

One parent specifically noted the pivotal role of health care team members in identifying when spiritual care might be beneficial:

"The nurse was extremely helpful. . .making suggestions for a chaplain."

### *Belief in the Transcendent Quality of the Parent-Child Relationship That Endures Beyond Death*

Some parents offered heartfelt, emotionally charged advice to other parents, emphasizing the undeniable love and transcendent nature of the parent-child relationship that never dies but rather continues beyond death:

"Keep talking to your child—let your child know that you are OK. That it is OK for them to go on. I held my daughter and never stopped talking to her, reassuring her. It helped me to tell her that she would always be with me, so strong in my heart."

"To know that [you] will never forget your child."

"Just remember that they lived a good life and you did everything possible for your children and also believe they are in no pain anymore and that their [sic] up in heaven happy and always watching over you like you watched over them and never forget how special they were."

### **Implicitly Spiritual Themes: Wisdom, Values, Hope, Trust, and Love**

Nearly half (46% [26 of 56]) of the parents in our sample identified implicitly spiritual resources that they had found helpful and offered as advice to other parents. These included wisdom borne of their experience; guidance according to one's own values; and virtues such as hope, trust, and love. These implicitly spiritual themes most often emerged in the context of advice to other bereaved parents. Wisdom that parents shared with others included the following:

"Listen, learn, accept, and let time do its job."

"Prepare yourself in advance if, as was the case in our situation, you know someday it is going to happen. . . . Finally, don't second guess the decision; think about it but to doubt yourself later on would eat you up."

"There will always be a void, but the pain eases."

"Don't blame yourself for things that were clearly out of your control. Believe [you] were terrific parents."

". . .[W]e must accept what will be. There is no answer to why this is happening. It is unfair and unjust and will never go away. We cannot change the situation no matter how hard we love or try."

Several parents advised others to honor and be guided by their own values as a way to approach difficult end-of-life decision-making:

"Based on your own values and decisions, make the best choice you can."

"Do what you feel is emotionally right for you, your family, and your child."

"Know when to say enough is enough."

"Ask yourself, would I want my child to have a poor quality of life if he/she survives?"

Some parents emphasized the value of drawing on traditional spiritual virtues, such as hope, trust, and love, to survive emotionally and to discover meaning in the child's death:

"Hope is essential, don't give it up. Even now, I realize that was so important."

"Never give up hope."

"Trust that the best people are doing the best they possibly can for your child."

"Put your faith in God and your trust in the skilled doctors and nurses at the hospital who are caring for your child."

"There are only 3 things that are everlasting—faith, hope, and love. Love being the most important."

“Tell your child you love them, no matter what.”

“I’ve learned a lot about the depth that some people are able to love or at least show love.”

Finally, some parents refrained from offering specific advice to other parents, spiritual or otherwise, some noting that each person’s situation was “too personal and subjective.”

## DISCUSSION

Our data corroborate previous findings that many parents value and rely on their spiritual resources to guide them in end-of-life decision-making, to make meaning of the loss, and to sustain them emotionally.<sup>11,12,25,35–38</sup> Parents identified 4 explicitly spiritual/religious themes of importance at the end of life: prayer, faith, access to and support of clergy, and belief in the transcendent quality of the parent-child relationship that endures beyond death. In addition, when parents reflected on what was most helpful to them and what advice they would offer to other parents, they frequently shared spiritual insight and wisdom learned from their own experiences and encouraged others to rely on their personal values and spiritual virtues, such as hope, trust, and love.

One of the most striking patterns of our data was that parents wrote much more freely about spiritual/religious beliefs and themes when they offered advice to other parents than to clinicians. Parents were more willing to share their spiritual and religious perspectives with other parents as evidenced by the frequency of spiritual/religious content, conversational tone, and emotion of their questionnaire responses. This suggests that although many parents experience the death of their child in spiritual ways, they may be reluctant to share this per-

spective with health care providers for any number of reasons, including the fear that their spirituality may be misunderstood or judged.<sup>13</sup> Perhaps parents fear that their spiritual perspective might detract from the medical care of their child or that their views might be marginalized in the largely secular, scientific medical culture of the hospital.

## Explicitly Spiritual/Religious Themes

### Prayer

Consistent with previous findings,<sup>12</sup> prayer was reported as helpful to a number of parents and was a practice that several recommended to other parents. Our data suggest that parents turned to prayer in times of medical crisis when medical care alone could not alleviate suffering or provide all of the answers.<sup>14,29</sup> We cannot be certain what the parents meant specifically by prayer because they tended to write merely, “I prayed a lot,” rather than elaborate. However, many diverse practices of prayer commonly are reported in health care settings (Table 1).<sup>5,39</sup> Prayer practices in the hospital setting can vary widely according to the number and the type of participants, location, physical posture, degree of formality, intent, sound, movement, devotional materials, and use of text. Given the number of parents in the sample who reported prayer as central to their coping efforts, creating an environment that is hospitable to and supportive of prayer is suggested. The clinician who is familiar with diverse practices of prayer will be better able to recognize the variety of devotional materials that parents bring to the bedside. The hospital can accommodate parental prayer practices by providing a multifaith chapel that has

**TABLE 1 Diversity in Prayer in Hospital Settings: Representative Range of Prayer Practice**

Participants	Solitary	Led by Chaplain or Clergy With Family and/or Patient	Prayers by Others in Community, Prayer Chains, Vigils
Location	At bedside	Hospital chapel or waiting room	Outside hospital at own place of worship
Posture	Kneeling, on floor or prayer rug	Sitting on chair or pillow	Walking, yoga, choreographed movement
Formality	Formal liturgy or prayer from one’s faith tradition		Spontaneous prayer in vernacular language
Intent	For specific outcome (guidance in decision-making, skill of the care team, success of procedure or treatment, the spiritual welfare of the dying)	For sustaining virtues (faith, hope, trust, acceptance, strength to endure, forgiveness, inner peace, etc), thanksgiving, confession	Companionship or union with the transcendent
Sound	Silent (meditation, contemplation, fasting, journaling)	Whispered or spoken	Chanted or sung; recorded sacred music
Devotional materials	None	Holy texts, icons, prayer beads, prayer rugs, prayer books, candles, tobacco, incense, crystals, crucifixes, amulets, scapulars, images of holy persons, string bracelets, holy water, blessed oils, prayer shawls, tefillin, head coverings, ritual foods, journal, prayer flags	
Use of text	Holy Book or selected passages displayed at bedside	Reading text silently or aloud; text study	Recitation of text

flexible space and a variety of devotional materials, is open at all times, and is convenient to the ICUs.

### Faith

“My faith” was reported as a reliable and helpful resource by a significant number of parents. Although there is not unanimity regarding the definition of faith,<sup>40</sup> our clinical experience suggests 2 general understandings. For some parents, faith refers to a set of beliefs that provide guidance and a context in which to find meaning. Seeking scriptural authority to assist in making medical end-of-life decisions, as reported by 1 parent, illustrates the belief model of faith. For others, faith refers primarily to the experience of trust, which was expressed by another parent in our study as, “Put your faith in God.” Although these 2 perspectives on faith need not be mutually exclusive, interventions that are consistent with a belief model of faith may not be synchronous with or might even offend parents who live out of a trust model of faith, and vice versa. Identifying a parent’s model of faith and customizing spiritual care accordingly are suggested.

### Access to and Care From Clergy

Although the death of a child is commonly understood in medical and biological terms, our data support the previous findings of Kirschbaum<sup>12</sup> that the death can also represent a spiritual struggle for parents, a crisis of meaning and connection. Several parents noted that the most helpful thing that staff did was to recognize their spiritual needs and to give access to and make welcome both community clergy and hospital chaplains on their behalf. One mother, for example, wrote about the pivotal role of her pastor in clarifying that the family had the scriptural authority to move forward with a decision involving withdrawal of life support. Had that conversation and follow-up collaborative work with the chaplain not been available, this particular parent may not have

been able to participate fully or with good conscience in the end-of-life decision-making process.

Accordingly, providers do well to inquire about whether parents are part of a faith community and whether they would wish to invite their clergyperson to the hospital. Families are often unfamiliar with the hospital chaplain’s role and availability and rely on clinical staff to introduce and offer such a resource.<sup>41</sup> In our data were examples of parents who had found comfort in their faith after the death of a child, of others who had come to a new spiritual understanding and meaning in life,<sup>5,35</sup> and of 1 mother who experienced profound spiritual distress and disconnection from her former faith.<sup>20</sup> Having access to a clergyperson with whom these issues can be explored is recommended as an important part of good holistic care.

Ideally, hospital-based chaplains and community clergy can partner in the spiritual care of families in crisis. Community clergy provide continuity of spiritual care for families—before, during, and after hospitalization—and are well grounded in the spiritual resources of their specific religious tradition. Community clergy, however, may not be familiar with the level of spiritual crisis or the magnitude of suffering that the death of a child can unleash for grieving parents. Hospital chaplains, in contrast, have special training and certification to work with people in spiritual distress across a range of faith traditions, as well as with people of no religious faith. Typically, hospital chaplains do not have the same long-term relationships with families that community clergy do, although families of children with chronic illness can be an exception to this generalization. The complementary roles of community clergy and hospital chaplains are summarized in Table 2.

### Belief in the Transcendent Quality of the Parent-Child Relationship That Endures Beyond Death

Some parents in our sample described the very special relationship that they had with their child and empha-

**TABLE 2** Complementary Roles of Community Clergy and Hospital Chaplains

Community Clergy	Hospital Chaplain
Acts as “primary” spiritual care provider	Acts as “hospitalist” spiritual care provider
Trains in 1 faith tradition	Trains in many faith traditions and existential and atheistic views
Provides sacraments, rituals, and prayers of 1 tradition in hospital setting	Provides (or arranges for) sacraments, rituals, and prayers of many traditions in hospital setting
Serves as consultant in medical ethics of 1 faith tradition	Serves as consultant in medical ethics of diverse faith perspectives
Engages in a long-term relationship with patient and family outside hospital	Engages in short-term relationship with patient and family in hospital setting
Serves as link to patient/family with faith community and its prayers, social resources (rides, meals, respite care), and financial assistance	Serves as link to patient/family with multidisciplinary team, hospital resources, and community clergy
Offers funerals in 1 faith tradition	Offers funerals for those without religious affiliation and for interfaith families
Provides long-term follow-up for spiritual distress and bereavement	Provides short-term crisis care for spiritual distress and bereavement

sized that the parent-child relationship had the capacity to transcend death. Consistent with earlier studies,<sup>11,42-47</sup> several parents found meaning and comfort in the belief that although the parent-child relationship would change after the death, it would not end abruptly but rather would be transformed and extend beyond this life. One parent visualized the child in heaven as a place without pain or suffering, another spoke of the legacy of memories not forgotten, and still another spoke about her child watching over them. One parent spoke of the child's continuing presence in her heart. How such beliefs might influence the way parents approach end-of-life decisions is unclear but worthy of additional study.

In some religious traditions, parenthood is understood to be stewardship of a child's life and a gift from God. Accordingly, God entrusts a child to a parent, and the parent then is responsible to God for the best care possible for that child. From this perspective, care providers might conceptualize parents as people who are trying their utmost to protect a life that has been entrusted divinely to their care. When disagreements and conflicts arise between parents and providers, admission of this spiritual perspective may allow for polarization to ease into greater partnership rather than conceptualizing parents as "difficult and controlling."<sup>48</sup>

### **Implicitly Spiritual Themes**

Nearly half of parents offered implicitly spiritual/religious responses with insight gained from their own experience, including wisdom, perspective, and guidance. Parental wisdom focused on the unfairness and injustice of the child's death, how much it was out of parental control, and the insight gained during bereavement. One parent in our sample poignantly described an inability to find meaning in the child's death and reformulated it as a mystery that could not be solved but must be accepted. Our clinical experience suggests that parents often wonder, "Is there some greater good (eg, research, organ donation, inspiration to others) in relation to which my child's death becomes acceptable?" "What was the reason for my child's death?" "Was it bad luck, or was it part of a bigger plan?" "Was my child's death a failure of some kind on my part to protect him or her adequately?" Even defining meaning in negative ways, as in "unfair" or "unjust," is to imply spiritual or existential expectations of justice.

Our data suggest that the meaning of a child's death for a parent is not viewed objectively but rather subjectively and constructed over time, typically out of difficult soul-searching.<sup>44,49</sup> In our sample, parents spontaneously offered wisdom, highlighting the importance of making meaning when faced with this type of loss. Meanings varied considerably. Families may benefit from access to caregivers who can listen and support them through their individualized search for meaning, which may take months to years.<sup>14</sup> One bereaved parent in our sample

reported distress when a doctor imposed his own meaning on their child's death, "As we stood by our child's crib in her final hour [the doctor told us that] 'It was just bad luck.'" Accordingly, one-size-fits-all wisdom is to be avoided by clinicians and chaplains alike.

Parents also emphasized the importance of doing what is right for one's child and family. For at least 1 parent in our sample, this included adherence to a particular religious process of confirming scriptural authority for any proposed decision, particularly withdrawal of life support. For another parent, it was defining one's own values regarding quality of life and setting a threshold for "when enough is enough." Being able to honor and follow one's values in medical decision-making may be considered spiritual for parents who try to live congruently with their sense of ultimate meaning. Whether the values are secular or religious, to the degree that they serve as an inner compass, they define a person's sense of meaning, obligations, and purpose in life.

Hope and trust were common themes in parents' comments. The parents in our sample did not specify the content of their hope but did emphasize its importance. Although what may be hoped for may change over the trajectory of a child's illness, the dynamic of hoping can remain in place to sustain a family's coping.<sup>50-52</sup> For example, early in hospitalization, parents may hope for a cure or "a miracle," but when it becomes clear that the child will not survive, parental hope may expand to include comfort and dignity at life's end.<sup>53</sup> Whether hope is expressed in religious or secular language, both hope and trust are forward-looking and may be considered spiritual. Hope and trust rest in the conviction that a larger trustworthy reality is present in the ongoing experience and may even transform the future in deeply meaningful ways.<sup>12,54</sup> Because hope motivates, it can serve as a creative and sustaining dynamic during long hospitalization and end-of-life care. Care providers may benefit families by helping members to identify for what they are hoping at any given point. Chaplains can help the team to understand better the parents' hopes, nurture realistic hopes, and "lift up" current hopes in prayer with the family.

Similarly, trust can help as a spiritual dynamic to sustain parents through the child's death and its aftermath. As noted earlier, several parents in our sample placed their trust in God, but trust can also be placed in secular resources. For example, 1 parent advised both by suggesting, "Have faith in God but also in the skilled doctors and nurses at the hospital who are caring for your child." Another parent viewed the care team as inherently trustworthy because God had provided them. Still another viewed the care team as trustworthy because of their medical and nursing excellence. This illustrates that the health care team itself can be perceived as a spiritual resource by some parents, the trustworthiness of which is highly valued.

Our findings suggest an abundance of love and compassion at the end of life in the PICU, embedded in a variety of relationships: parent-child, sibling-patient, friends-parent, staff-patient, and staff-parent. One parent reported that of all virtues, love was “most important and everlasting.” Another parent commented that “the depth of love” in the PICU was most helpful at the end of the child’s life. Religious traditions commonly identify love as one of the central aspects of spiritual experience. Among Christians, for example, love is understood to be a manifestation of God and therefore transcendent.<sup>55</sup> Our previous work<sup>9,30</sup> and that of others<sup>56–59</sup> have documented that parents value emotional expression, compassionate presence, and kindness from their child’s health care team members. Beyond professional competence, parents want to know that their situation is seen as unique, compelling, and worthy of the caregivers’ compassion.<sup>11,60</sup> The variety of compassionate caregivers cited in our sample was remarkable. Some parents identified the value of “the doctors and nurses who were right with us,” another noted, “the man who cleaned up the mess everyone made was probably the most helpful of all,” and yet another parent stated that “everyone cared for our son as if he were their own.” Our findings are consistent with previous research suggesting that when care team members offer appropriate gestures of kindness and compassion and show their own humanness, families often feel supported spiritually and find it easier to access sources of hope, trust, relationship, and meaning.<sup>13,14,28,59–62</sup> Moreover, caring emotional attitudes

that are displayed by pediatric intensive care clinicians have been associated with beneficial short- and long-term effects on parental bereavement.<sup>58</sup>

### Clinical Implications

Our data lend additional support to studies that have documented the immediacy and the abundance of parental spiritual needs in the PICU.<sup>11,30,51</sup> The American Academy of Pediatrics<sup>16</sup> and the Institute of Medicine,<sup>63</sup> in their groundbreaking book *When Children Die*, emphasize the clinical and ethical imperatives of incorporating spiritual needs assessment and care at the end of life. The Joint Commission on Accreditation of Healthcare Organizations mandates that a patient’s spiritual needs be both assessed and accommodated.

Clinically, we find it useful to apply both a generalist and a specialist approach to the provision of spiritual care.<sup>28</sup> Clinicians can aim to be spiritual generalists and medical specialists, whereas chaplains can aim to be spiritual specialists and medical generalists. For example, doctors and nurses can assess the broad spiritual concerns of patients and families to refer them to appropriate spiritual advisors, whereas chaplains must take into account the medical issues, plan of care, and prognosis to understand the context from which spiritual needs emerge and to anticipate impending spiritual crises. Ideally, both clinicians and chaplains are nonjudgmental and open to diversity of spiritual beliefs. In all cases, they should refrain from proselytizing. Whenever possible, PICUs should include professionally certified chaplains

**TABLE 3** Roles and Tasks of Spiritual Care Generalists and Specialists

Spiritual Care Generalists (Clinicians)	Spiritual Care Specialists (Chaplains) in Addition to Generalist Care
Model comfort in talking about spiritual issues, and hospitality for all religious traditions and spiritual practices	Be knowledgeable about a wide variety of religious traditions and spiritual practices; provide caregivers with relevant information about specific faith traditions and the medical setting
Do not disclose or “sell” own beliefs	Develop customized family-centered spiritual care plan.
Notice spiritual or religious materials at bedside or on person	Support spiritual practices that are important to the patient/family; facilitate accommodations as needed
Listen for spiritual talk (“This was meant to be.” “It’s in God’s hands now.” “I pray that . . .”)	With permission, link with faith community
Listen to the feelings, worries, suffering, guilt, and meaning-making that parents express; foster realistic hope	Provide devotional materials, if requested
Notice signs of spiritual distress (“Why is this happening to us?” “Why isn’t God hearing my prayers?” “I feel like we are being punished.”)	Ethical consultation from a faith perspective, if requested
Provide opportunities for parents to express grief, joy, anger, frustration, and hope	Identify and explore issues of spiritual distress, worry, suffering, and guilt Identify spiritual strengths, hopes, and relationships of trust
Explain role of chaplain; offer services	Include parental concerns and hopes in intercessory prayer, sacrament, and ritual
Include chaplain in care team meetings and multidisciplinary rounds	Provide informational materials to staff and families
Build trust with parents; be punctual; keep your promises	Attend team meetings and interdisciplinary rounds
Provide space and privacy for a variety of prayer styles	Build trust with parents; be punctual; keep your promises.
Refer prayer requests to chaplain; stand in respectful silence if family prays at bedside	Develop familiarity, comfort, and skill in a variety of prayer styles
Orient to multifaith chapel, quiet space for prayer 24/7, regular worship opportunities	Pray with parents in their own language, style of prayer, and tradition; include their current hopes, concerns, fears, and spiritual distress, as appropriate
	Locate chapel conveniently to ICU and operating room
	Ensure that chapel space is barrier-free and hospitable to people of multiple faiths and accommodates multiple prayer styles
	Equip chapel with devotional materials in a variety of languages and faith traditions
	Offer worship opportunities that are representative of the hospital community

as integrated members of care teams.<sup>64</sup> Collegial, collaborative working relationships and interdisciplinary team care coordination are essential.<sup>30,64</sup> Table 3 summarizes and distinguishes the roles and tasks of spiritual care generalists and specialists, and Table 4 offers suggested sample assessment questions for each.

All team members, given training, experience, and motivation, have the capacity to provide a generalist's level of spiritual care, with its incumbent active hospitality to the family's spirituality.<sup>14,28</sup> Many medical and nursing schools now offer educational opportunities for integrating spiritual issues responsibly into practice. Other options for training include specialized programs that adapt basic chaplaincy training to other disciplines, such as the Kenneth B. Schwartz Fellowships in Pastoral Care.<sup>59,65</sup> Of course, it is important that clinicians recognize when to consult chaplaincy when the family's spiritual needs exceed their generalist level of expertise. Table 5 offers guidance for clinicians regarding when they should seek such consultation.

### Limitations of the Study

Several limitations of the study must be acknowledged. The sample size was relatively small and consisted of predominantly white, English-speaking parents. Half of the parents identified themselves as Catholics, reflecting local demographics, which may limit generalizability. The response rate (58%) was at the low margin of the acceptable range for such studies, and the individuals' willingness to participate may reflect bias in their clinical experiences, views of end-of-life care, degree of emotional recovery, or ability to read and write their responses to the questionnaires. The questions on the survey of parental perspectives on end of life did not specifically ask about spirituality or religion; however, parents spontaneously offered many spiritual/religious responses, suggesting the importance and the centrality of these issues. It was not possible to determine whether the respondents differed significantly from the nonre-

**TABLE 5 When a Spiritual Generalist Should Consult A Chaplain**

A spiritual generalist should consult a chaplain when:
Families desire spiritual support in a difficult time
Someone requests prayer, sacraments, ritual, or devotional materials
Patients or families wish to include a faith perspective(s) in their decision-making
Faith is a primary source of comfort, strength, and community for those in the staff's care
Staff notices signs of spiritual distress: "Why is this happening to us?" "Why isn't God listening to my prayers?" "I feel like I am being punished."
A caregiver wishes more information about a faith tradition and its relevance to medical care
The patient or the family voices religious or spiritual objections to the plan of care
Families need special accommodations for spiritual or religious observance
Interfaith families need an interfaith team of spiritual caregivers
Staff observe religious solicitation in the hospital setting

spondents, because the questionnaires were administered anonymously to foster candor. The study included parents of children who represented a full range of ages and disease processes and for whom the time since death varied widely, precluding the ability to draw specific conclusions about the spiritual aspects of particular kinds of death trajectories, diagnoses, or the impact of time elapsed since death. Last, the study was subject to the limitations that are inherent in all studies that depend on self-report measures.

### CONCLUSIONS

Many parents in the PICU drew on and relied on their spirituality to guide them in end-of-life decision-making, to make meaning of the loss, and to sustain them emotionally. Parents reported 4 explicitly religious/spiritual themes: prayer, faith, access to and care from clergy, and belief in the transcendent quality of the parent-child relationship that endures beyond death. In addition, parents identified several implicitly religious/spiritual themes: insight and wisdom; reliance on values; and spiritual virtues such as hope, trust, and love. Staff mem-

**TABLE 4 Suggested Sample Assessment Questions for Spiritual Care Generalists and Specialists**

Spiritual Care Generalists (Clinicians)	Spiritual Care Specialists (Chaplains)
Do you consider yourself spiritual or religious?	Where is God in all of this?
Do you have a religious preference or spiritual path?	What aspects of your faith are giving you the most comfort and strength right now?
What is giving you the strength, comfort, and hope you need right now?	How do your spiritual beliefs influence how you view this illness right now?
Do you need any special accommodations for your spiritual or religious needs while you are in the hospital? Dietary needs?	Are there parts of your spiritual life that are troubling you right now?
Document information and refer to chaplain as appropriate.	Do you have a faith community, and would you want to include them at any point?
	I wonder whether there are ways that your faith affects the medical decisions that you are making these days.
	How have your religious or spiritual practices changed over the years?
	Document information as appropriate.

bers, hospital chaplains, and community clergy are encouraged to be explicit in their hospitality to parents' spirituality and religious faith in the PICU, to foster a culture of acceptance and integration of spiritual perspectives, and to work collaboratively to deliver spiritual care. In this way, parents may be more forthcoming about their spiritual and religious perspectives that may influence their meaning-making, decision-making, and ways of coping.<sup>13,14</sup>

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## Matters of Spirituality at the End of Life in the Pediatric Intensive Care Unit

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