

Symptom Management of Spiritual Suffering in Pediatric Palliative Care

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Children with life-threatening conditions may encounter significant spiritual suffering as they anticipate and prepare for their impending deaths. This pediatric palliative care case study illustrates symptom management challenges related to spiritual suffering of a dying adolescent. The nurse plays a critical role in identifying the pediatric patient's verbal and nonverbal cues that may denote spiritual problems, as well as patient, family, and environmental factors. Evidence-based clinical practice guidelines are available to facilitate symptom management of spiritual suffering in pediatric patients across disciplines and within the community. This article highlights the nursing role in assessing and managing symptoms of spiritual suffering in children living with life-threatening conditions. The complexity of spiritual suffering in the pediatric palliative care population emphasizes the need for an interdisciplinary team approach and the integral role of the nurse in providing spiritual support at end of life.

KEY WORDS

pediatric palliative care, spirituality, spiritual suffering, symptom management

More than 53,000 children die each year in the United States.¹ Dying children may experience negative consequences from substantial suffering across multiple quality-of-life domains at the end of life.²⁻⁴ For example, they may show signs of physical (eg, pain, nausea, vomiting, fatigue), psychological (eg, depression, anger, guilt), social (eg, lack of communication with family members, isolation from peers), or spiritual suffering (eg, meaning of life, death, or illness experience;

grief for current and future losses). Spiritual suffering may especially surface when terminally ill children anticipate and prepare for their impending deaths. Spiritual suffering can manifest as lack of meaning, hopelessness, grief for loss of future, worry about being forgotten, or concern for loved ones they will leave behind.⁵⁻⁸ Although some studies have included issues of spirituality in children with life-threatening conditions,⁹⁻¹¹ more work is needed to promote evidence-based practice in symptom management of spiritual suffering in dying children. This article includes presentation of a case study illustrating a symptom management challenge related to spiritual suffering in pediatric palliative care. Recommendations to guide assessment, suggested symptom management based on available evidence, and key implications for hospice and palliative nursing are provided.

CASE PRESENTATION

Sixteen-year-old Reid was diagnosed with acute myeloid leukemia (AML). He is president of his student class, active in his church youth group, and excited to have recently gotten his driver's license and first car. Reid lives with his mother, father, and 14-year-old brother. Family and friends are inspired by Reid's positive outlook on life and consistent positive attitude that he is going to beat this disease.

Reid was diagnosed with AML in March. As he threw the first pitch of his high school baseball game, his bald head was evident beneath his ball cap. But that didn't bother Reid. He was a fighter, always living life. In July, 4 months after diagnosis, he had an allogeneic hematopoietic stem cell transplant. Reid's preparatory regimen included total body irradiation and high-dose chemotherapy. As a result, he experienced severe mucositis pain, nausea, and vomiting after transplantation. The transplant eventually grafted, and he went home in September. Reid had a few hospitalizations for fever and neutropenia but enjoyed life away from the hospital. He celebrated his 17th birthday. About 4 months later, Reid's AML relapsed. A decision was made to treat the leukemia in hopes of obtaining remission so that a second transplant could be done. Reid spent the next

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2 months in the hospital as his disease continued to progress despite aggressive treatment. His complications included temporary paralysis, urinary retention, and vision problems, secondary to proliferation of myeloblasts (chloromas). During this time, Reid relied on a few nurses, especially Randy and Joy, and confided in them during his hospital stay. At times, there were pervasive sadness and frustration that things were not turning out as he had hoped. At one point, he shared: "Just in case something happens, I really want to do something that nobody else has ever done. You know, to leave my mark. So that people will always remember that I did something that really mattered."

Reid pushed onward, fighting to hold onto life and willing to do whatever it would take to beat all the odds. Then he developed another infection, and his leukemia progressed further. The medical team gently shared with Reid's mother and father that cure was unlikely, and goals of Reid's care should shift to decreasing suffering and enhancing quality of life. Before the case conference ended, Mom stated, "Reid is not stupid. He knows exactly what we are talking about in here. He deserves to hear this same information from his medical team..."

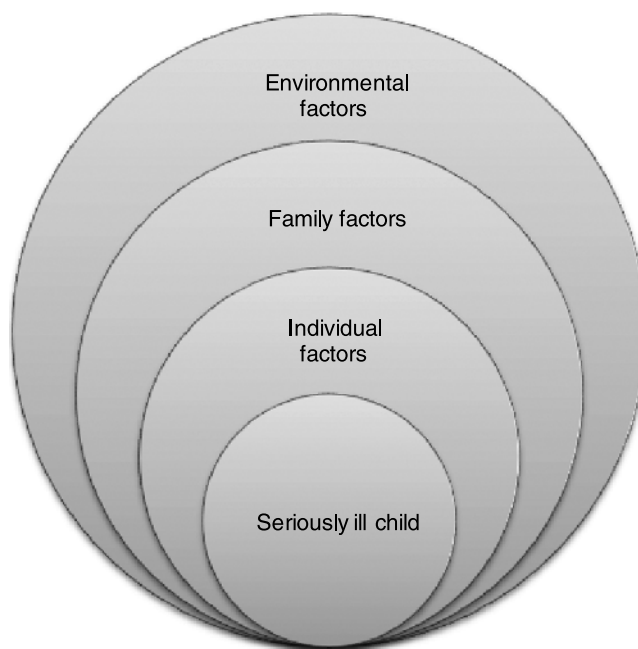


FIGURE 1. Illness-related factors to consider in assessment of seriously ill children.

ASSESSMENT OF SPIRITUAL SUFFERING

Definitions of spirituality are many and include seriously ill and dying children's: (1) beliefs about life and death, (2) search for meaning and purpose within the illness and dying experience, and (3) self-awareness or knowledge of inner being, faith, hope, or dreams for the future and may include (4) spiritual, religious, or cultural rituals.^{6,7} Spirituality is a progressive journey for children living with life-threatening conditions and their families as their spiritual perspectives may parallel the ups and downs of their illness experience.⁶ While some terminally ill children may experience spiritual growth during their illness and death, others may experience spiritual suffering. When a dying child such as Reid experiences spiritual distress or suffering, healthcare providers may be challenged to determine a treatment plan.⁷ Assessment of spiritual suffering in children living with life-threatening conditions is a progressive multidimensional activity that occurs over time. Recognizing symptoms of spiritual suffering begins with the healthcare provider being alert to illness-related factors across multiple domains within the context of living with a serious or life-threatening illness (Figure 1), such as:

1. Individual factors
 - a. child's developmental level and ability¹²⁻¹⁵ (Table 1).

- b. child's physical experience of discomfort and family's ability to tolerate it.
- c. child's experience of emotional symptoms (eg, anxiety, fear, agitation, anger, frustration, hostility, irritation, resentment, insecurity, misery, loneliness, sadness).

2. Family factors

- a. family members' ways of coping with child's suffering.
- b. family communication (effectiveness of complex communication channels among child, family, and healthcare team).
- c. religious or cultural background (preferences, beliefs, rituals of child and family).

3. Environmental factors

- a. Living situation (place of care, eg, home, hospital, hospice).
- b. Social support (peers, community, healthcare team, etc).

Use of structured tools has been recommended to guide clinicians' spiritual screenings, histories, and assessments.⁸ For example, the FICA¹⁶ and HOPE¹⁷ offer guides for taking a spiritual history. Assessing parameters of hope could be informed by the Children's Hope Scale, a 6-item dispositional self-report index that has been validated for use with children aged 8 to 16 years.¹⁸ Scales measuring preparatory grief¹⁹ and quality of life at the end of life²⁰ address spiritual and existential concerns, although developed for adults rather than pediatric populations. However, these adult measures could inform

**TABLE 1** Developmental Understanding of Death

Age, y	Developmental Understanding	Death Concept	Examples of Death Understanding
1-3	Death often seen as continuous with life. Death and life are similar to awake and asleep.	Does not understand irreversibility or permanence	"When will he [deceased person] wake up?"
4-5	Death is seen as temporary and reversible; may also see death as a punishment, or struggle with guilt because he or she is dying.	Does not fully comprehend the concept of irreversibility or permanence; believes in magical thinking or that you can wish someone dead	"Once you are dead are you always dead; but how long do you stay dead?"
			"I have been bad, so now I have to die."
			"I am sorry that I am not getting better."
6-9	Understands death is permanent. Begins to realize people he or she knows will die and that dying means living functions will stop. A dying child may continue to experience guilt and shame for dying.	Understands irreversibility and begins to understand finality or nonfunctionality: heart stops, you do not breathe, etc	"Will dying hurt?"
			"Is dying scary?"
			"I know that your heart stops beating and you stop breathing, but what do you do when you are dead?"
			"I am sorry that I am not getting better."
10-13	Understands death is permanent and that living functions cease. Begins to understand death is universal.	Understands irreversibility and nonfunctionality and begins to understand universality	"I'm afraid if I die, my mom will break down. I'm worried that if I die, I will miss my family or forget them or something."
14-18	Thinking becomes more abstract. One can objectively examine death. An adult understanding of death develops. However, death may be viewed as an enemy that can be fought against. Therefore, dying may be viewed as a failure.	Understands irreversibility, nonfunctionality, universality, and causality	"Everyone dies, it is part of life."
			"Death can happen from an accident, or an illness, or from a shooting, or something like that."
			"It is no one's fault that I am dying, but I am going to do everything I can to fight against it."
			"I can't believe I'm dying. This is so unfair! This stupid cancer has made me look awful."

Adapted from 12-15.

future development of similar developmentally appropriate measures for children. A recent study explored spiritual quality of life in children with advanced cancer using open-ended questions to assess relationships with a higher being, with self, and with others.¹⁰ Open-ended questions may be extremely useful for exploring a child's perspective regarding possible spiritual suffering.²¹ McSherry et al⁷ have provided examples of open-ended questions that could be used in assessing spiritual needs of children, such as "What help would like in thinking about religious or spiritual issues?" or "What does your family [or you] believe about what happens after death?"^{7(p616)}

Assessment should also include identification of verbal and nonverbal cues that may represent spiritual suffering. Children may express their spiritual suffering through play, drawings, games, facial expressions, or dreams.^{6,21,22} A fear of being alone could be indicated by a child's increased sensitivity to separation, without explicit reference to death.²³ Dying children are often greatly concerned for loved ones they will leave behind^{5,23,24} and may say things such as "Don't worry, I'll be OK." One spiritual concern for some children²⁵ is embodied in legacy, including their accomplishments and the difference their life has made to others. For example, Reid expressed that he wanted to

do something nobody else had ever done to leave a mark that others would remember. Some children may want to intentionally leave behind a legacy, such as giving away special gifts.²⁴ While some children display spiritual suffering through nonverbal actions or behaviors, others may explicitly articulate their concerns. A teenager may struggle with the meaning of the illness with indirect statements such as, "I can't believe I am dying... why is this happening to me?" Younger children may express concerns about end of life (eg, "Will dying hurt? Is dying scary?") to his/her family members. A benefit of conducting a spiritual assessment is the identification of possible spiritual problems or needs of the dying child (Figure 2).

MANAGEMENT OF SPIRITUAL SUFFERING

After assessing spiritual suffering and identifying spiritual needs, appropriate management can be determined and implemented. The goal of addressing spiritual suffering is to facilitate the ill child's own encounter with

spirituality and existential issues related to their dying.²⁶ The National Consensus Project for Quality Palliative Care²⁷ developed evidence-based clinical practice guidelines that can assist healthcare clinicians in the management of spiritual suffering (Figure 3). Recommendations include (1) involving professionals with expertise in responding to spiritual and existential issues common to children and their families; (2) regular, ongoing exploration of spiritual concerns; (3) identifying religious or spiritual/existential background; (4) facilitating contact/support from spiritual communities, groups, or individuals; (5) being sensitive to use of religious symbols in light of cultural and religious diversity; (6) facilitating child's use of own religious/spiritual symbols; and (7) periodic reevaluation across the illness trajectory. In Reid's case, with his parents' permission, one of his nurses and a child life specialist met with the other players on his baseball team who were extremely close to Reid and talked with them about ways in which they could stay connected with Reid through e-mails and cards. His friends were encouraged to remain an integral part of Reid's journey.

Concern about life after death	• Will it hurt to die?
Loneliness	• None of my friends play with me anymore.
Fear of not being remembered	• I'm worried that everyone will forget me.
Angry towards others/God	• Why did God let me get cancer? This isn't fair.
Desires relationship with God	• Where is God when I need Him most?
No value in life	• I have nothing to be proud of.
Loss of future, relationships, self, health	• I'll never even be able to graduate from high school with my friends.
Feels guilty of doing something wrong	• What did I do to deserve this?
Needs unfinished business to be resolved	• I wish my Dad knew how much I love him.
Separated from peers or community	• I'm so weak, I can't even go to school anymore.
Questions belief system/rituals	• My grandma prays for God to heal me, but I don't really find that helpful anymore.
Struggles to find meaning in illness	• I don't understand why this is happening to me.

FIGURE 2. Examples of spiritual problems identified by verbal cues from dying children.



FIGURE 3. Guidelines for the management of spiritual suffering.

Holistic care is vital to delivering the best care to children suffering and dying of life-threatening or life-limiting conditions. Management of spiritual suffering requires the ability to decipher the complexity of spirituality and may include advocacy related to physical, psychological, or social domains of care.^{6,9,28} These domains are interwoven and can influence one another. For example, negative physical symptoms (eg, pain, cachexia) may trigger a child to anticipate death and develop a fear of being forgotten. Management of this spiritual suffering may first require good physical symptom care so that the child can then focus on discussions about death-related fears or have the ability to focus on participation in a legacy-making activity. In turn, some spiritual interventions may decrease suffering within physical, psychological, or social realms, by allowing the child or adolescent to give meaning to their experiences or give voice to their struggles.

Examples of spiritual health interventions are exemplified in the everyday activities of the nurse. For example, nurses take the time to listen and actually hear the struggle or “be” in the presence of suffering. Other examples include therapeutic communication (eg, compassionate presence, open-ended questions to facilitate child’s feelings, life review/listening to child’s story), therapy, and self-care (eg, art therapy, music therapy, storytelling, legacy making).^{8,24} Previous studies show that some of these interventions can reduce various domains of suffering among pediatric palliative care patients. For example, Klosky et al²⁹ evaluated an interactive intervention

for 2- to 7-year-old children with cancer. The cognitive-behavioral intervention package included an interactive animatronic plush character, an educational video, and passive auditory distraction via Barney narrated stories. Klosky et al²⁹ concluded the interactive intervention was effective at reducing radiation therapy–related distress of children with cancer as measured by heart rate. Robb and Ebberts³⁰ explored a songwriting and digital video production intervention as a means for promoting self-expression and positive coping in eight children (aged 9-17 years) undergoing bone marrow transplantation (BMT). Findings suggested that the music-based intervention may help children undergoing BMT identify and develop personal strengths that would improve their coping. Burns et al³¹ explored a therapeutic music video intervention for adolescents and young adults during stem cell transplantation and found positive trends among hope, spirituality, confidence, self-transcendence, symptom distress, and defensive coping. Ewing³² presented wish fulfillment as a palliative care intervention for dying children that can ease suffering and sorrow for the child and family. Although similar activities have previously been described as “spiritual health interventions,”⁸ few studies have examined the effects of interventions on spiritual suffering outcomes within pediatric palliative care, especially at end of life. More research is needed in the pediatric palliative care population to address spiritual needs and to minimize spiritual suffering of children and their families.

IMPLICATIONS FOR PALLIATIVE NURSING

Pediatric palliative care and hospice nurses play a vital role in the assessment and management of spiritual suffering in terminally ill children and their families. Advanced practice nurses can assist in coordinating communication among the ill child, family, and healthcare team in regard to spiritual needs or concerns. Nurse practitioners can identify when appropriate referrals to or consults with spiritual experts, such as chaplains, are needed. Nurses at the bedside, who typically have well-established relationships with ill children and their families, are in ideal positions to identify children with spiritual concerns and help facilitate related conversations. They can provide support to families as they cope with questions about life that arise from apparent powerlessness, helplessness, and meaninglessness inherent in the family’s experiences. Nurses can recognize when private communication may need to occur between the nurse and the ill child versus facilitating discussions between the ill child and his/her loved ones. Attentive healthcare providers are in key roles to be helpful to children and families when they facilitate a safe place where a mutual kinship of spiritual needs, uncertainty, and hope reside among providers and recipients of care alike.³³

Some children may benefit from guidance in concrete activities to address their spiritual suffering (eg, Reid could be guided to write a letter to express his love and concern to a family member or friend). Other children may need reassurance or help in cognitively reframing their situation. For example, Reid expressed that he wanted to do something to “leave his mark.” The nurse could assist him to generate feasible ideas to accomplish this goal but could also assist Reid to realize and identify an already established legacy such as being an excellent role model to his younger brother. Nurses can help family members and other members of the healthcare team recognize when manifestations of spiritual suffering may signal the ill child’s grief or progression in their understanding of death or death awareness.

Although life-threatening conditions may prompt spiritual suffering in children and their families, studies also show positive consequences such as benefit finding³⁴ and positive meaning of illness.³⁵ Furthermore, spiritual beliefs are not unequivocally helpful to all children and their families, as they may be having spiritual struggles (with their faith, spiritual beliefs, etc) when dealing with impending death.⁶ Conceptual models, protocols, algorithms, and structured instruments can help direct our assessment and management of spiritual symptom challenges in pediatric palliative care while remembering that each child and family requires individual care. We may learn a great deal by adopting an attitude of “Please teach me about....” Opening the door for these child and adolescent experts to teach us more about their journey will allow us to better hear the “child’s voice”³⁶ and gain a better understanding for how to improve the assessment and management of spiritual suffering.

CONCLUSION

...The team agreed and accompanied the parents to Reid’s hospital room. Prior to discharge, the nurse, Joy, negotiated some uninterrupted time on the unit to facilitate a discussion with Reid and his mom about his life goals and things he wanted to accomplish. Joy offered suggestions for things that some other teens in similar situations had found to be helpful, such as making a will, writing letters to important people, or giving away special gifts.

After his year-and-a-half battle, Reid died after spending 6 weeks at home lovingly surrounded by life with his family and friends. Several weeks later, Mom sent a letter about how Reid’s wishes were carried out as much as possible: The hearse peeled out of the driveway as Reid had requested. He planned his own funeral. He willed

his car to his younger brother. He left letters behind for his mom and dad. He designed T-shirts that he gave to all of his family and friends; the front included a saying used a lot by his baseball coach, “Attitude is everything!” which had become a real source of strength for Reid as he was dealing with life. The back included Reid’s picture, on the baseball mound with his ball cap, experiencing life and smiling.

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