STUDY EXPLORES CHILDREN’S SPIRITUAL CARE, AND THE NURSE’S ROLE, AS A KEY PART OF PALLIATIVE CARE

A study recently published in the Journal of Palliative Medicine explores the experiences of nurses in communicating with children about their spiritual needs, with the objective of developing training in this area. Caring for patients who are dying or seriously ill is a huge challenge for nurses, especially when the patient is a child. Palliative care understands that even beyond pain and symptom management, there is a need for care for the whole person. This includes caring for the spiritual well-being of children experiencing life-limiting illness. “The spiritual needs of ill children and their families include the need for religious rituals, to reframe hope, to enhance the transcendental nature of meaning-making of the child’s illness, to explore the meaning of their child’s life and death, and for bereavement care.

“Despite the ubiquitous nature of spirituality throughout pediatric care, the predominant focus of palliative care communication in pediatric settings has centered on shared decision making between parents and clinicians, with an emphasis on the skills of the clinician to provide information and to allow families to express their wishes for the child’s quality of life.” While clinical care is critical, there is also a need for discussions around the spiritual reality of end-of-life, and the needs of children and their families from a spiritual or existential perspective. “This type of communication recognizes the spiritual presence of the deceased child, de-medicalizes the child’s death, and reinforces continued relationship bonds with the child that will assist in bereavement.”

While communications skills are widely recognized as a key component of pediatric palliative care, little has been known about the appropriate content for a curriculum on spiritual care. Even for experienced nurses, spiritual communication is one of the most difficult parts of their work. “Nurse-initiated discussions about spiritual concerns with patients and family members are uncommon, and nurses are likely to transition to another topic in response to caregiver- or patient-initiated spiritual communication.” The authors hope that, by studying the experiences of nurses attempting to communicate with children about spirituality, helpful communication training can be developed.

Researchers have found that four major themes emerged in survey answers completed by 30 nurses who participated in the voluntary study. Each theme reflects the content of spiritual communication with seriously ill children, including: Spiritual questioning, Discussing the afterlife, Sharing descriptions of heaven, and Hearing God’s call.

Spiritual Questioning: Nurses report that their pediatric patients often have questions about faith and spirituality. Many question why they are facing death at such a young age, and question whether God is just. Common questions include: “Why do bad things happen if God is good? Am I going to die? What does God want me to do? Why did all of this happen?” Of all the people in the health care team, the nurse is best positioned to have these conversations in a natural way. Sometimes, nurses may act as intermediaries between the child and parents who share different belief systems.
**Discussing the Afterlife:** Children experiencing serious illness frequently speak with their caregivers about what comes after death. Nurses shared that ill children innately understand that their lifespan is limited, and that the children themselves formed a community in the hospital, to encourage one another in their transition to the afterlife. “As a group, the ill children shared a belief that they would reunite on the other side; they spoke of awaiting each other’s arrival, having welcoming parties, and helping each other cross over. Ill children discussed the afterlife without fear, sadness, or pain.” Visions of angels and the dead are very common among seriously ill children, and nurses often find themselves in the role of explaining the child’s visions to parents who are sometimes skeptical.

**Sharing Descriptions of Heaven:** Visions are also central to children’s descriptions of heaven. “The children spoke of heaven without any fear. Nurses perceived that these accounts served to reassure parents that even though their child’s death would be very hard to accept, the child’s belief in heaven made them comfortable and unafraid. Nurses reported that this seemed to give parents peace in the midst of a very painful journey.” Children frequently told their parents that they would be waiting for them “on the other side.”

**Hearing God’s Call:** Children often talk with nurses about hearing God calling them, and leaving with God. One nurse shared an instance in which a child, who had been unresponsive for 50 days, sat “bolt upright and said aloud in a firm voice, ‘Can you all be quiet? God is calling me and telling me how to find him and I can’t hear him, you are too loud.’” She died a short time later. Nurses said that children’s spiritual expressions are related to the religion and culture of the family, and that a part of their job is to be sensitive to the particular needs of each family’s religious understanding.

**Conclusions:** The nurses surveyed agreed that they have a vital role to play in spiritual care for dying children, making the end-of-life process as easy for them as they could. “For the children and for the families, nurses are present, with angels, miracles, voices, and their loved ones, to escort them on the illness journey. Nurses described that they did not need to speak or do anything at all for their patients, except be by their side and be present.” Nurses acknowledge that a part of their preparation for this work is to spend time exploring their own spirituality, so that they can engage authentically with their patients.

Based on this study, researchers conclude that a curriculum would be helpful for nurses to dying children and their families. “Communication training should include ways to respond to a child’s spiritual questioning, how to engage in a discussion of afterlife, and how to facilitate discussions about heaven between child and family ... Spiritual communication training may be offered as a continuing education program and should include faculty with expertise in chaplaincy, nursing and communication. Chaplains serve as spiritual care experts and can help train nurses to screen for spiritual distress, to have greater competence in spiritual communication, and to collaborate with chaplains in care.” ([JPM](#))