CE 2.5 contact hours

Design Pics Inc/Alamy Stock Photo

Faith, Hope, and

SUPPORTING PARENTS WHEN THEIR

Cheryl L. Crisp, PhD, PCNS-BC, CRRN, is an Assistant Professor at Purdue University, Columbus School of Nursing. Cheryl is the adoptive parent of two children with medical special needs, one of whom has already died, and the other who has had several near-death experiences.

Accepted by peer-review 1/2/2015.

The author declares no conflict of interest.

DOI:10.1097/CNJ.0000000000000202

ABSTRACT: *When a child has a life-limiting illness, parents' goals and strategies for their child's life may need to be drastically altered, especially if early death looms. This article reviews literature and research about how families employ faith, hope, spirituality, and biblical perspectives as their child becomes critically ill and faces death. Suggestions are made for best caring practices for families and children encountering this difficult journey.*

KEY WORDS: *communication, end of life, faith, hope, life-limiting illness, nursing, pediatric palliative care, spiritual care, spirituality*

Jesus said, "Let the little children come to me, and do not hinder them, for the kingdom of heaven belongs to such as these" (Matthew 19:14, NIV).

By Cheryl L. Crisp

Spirituality:

R CHILD HAS A LIFE-LIMITING ILLNESS

An important goal for parents is to assist their children to become happy and healthy adults. However, this is not always possible for parents of children who are medically fragile, have chronic illnesses, or become critically ill. Goals and strategies for life planning may need to be drastically altered to meet the needs of the child and family, especially if a possible outcome is the death of the child. Families frequently employ the concepts of faith, hope, and spirituality to guide them as their child nears death.

The National Vital Statistics Report notes that 5,279 children, or 12.9 out of every 100,000 children aged 5 to 14 years, died in 2010 (Murphy, Xu, & Kochanek, 2013). The majority of deaths were related to accidents or long-term illness, such as cancer. One wonders how many of these children were prepared for death by their loved ones.

Various cultures and ethnicities approach death differently, but regardless, numerous studies reveal that spirituality is important to families who have a child with a life-limiting illness (Aschenbrenner, Winters, & Belknap, 2012; Knapp et al., 2011; Robinson, Thiel, Backus, & Meyer, 2006; Rosenbaum, Smith, & Zollfrank, 2011). Families employ faith and hope, even as the child is nearing death, sometimes to the consternation of their child's healthcare providers (Brierley, Linthicum, & Petros, 2013; Weiner, McConnell, Latella, & Ludi, 2013). The loss of hope may feel like giving up, and parents never want to give up. Some parents may believe that if they have faith like a mustard seed (Mark 4:30-32), anything can happen. However, in general, parents who have a strong faith are more likely to hold to hope, whatever the outcome.

Christian parents can learn much from the story of King David (recorded in 2 Samuel 12), who lost a child shortly after birth. David prayed unceasingly as the babe was dying. Parents can follow David's example of asking for God's guidance, wisdom, and comfort. David kept praying, hoping, and believing that his baby would be healed, but through much prayer, eventually accepted that God had other plans. David kept praying for strength and wisdom once the baby had died. His faith in God never wavered, in spite of his heartbreak. David's heartbreak and faith were real. His example provides hope for parents reeling from loss.

The purpose of this article is to describe the concepts of faith, hope, and spirituality, and how these might be employed by families of a child with a life-limiting illness, to guide them through this difficult process. "The LORD is near to the brokenhearted and saves those who are crushed in spirit" (Psalm 34:18, NIV). Families who hold this belief typically have multiple sources of strength to help them through the child's end-of-life care.

FAITH: AN IMPORTANT TOOL

Faith is an important tool parents and healthcare providers use when caring for a dying child. Faith is a deep-seated feeling that at some point all will be well. In the Christian tradition, faith is a strongly held belief that the child will be healed according to God's will. "Now faith is being sure of what we hope for and certain of what we do not see" (Hebrews 11:1, NIV). Parents of children receiving palliative care have reported faith as the basis for decision-making, making sense of their situation, guidance in daily existence, for end-of-life discussions, and as a way of coping with the current circumstances (Meyer, Ritholz, Burns, & Truog, 2006; Robinson et al., 2006). Faith may lead the family to ask that a chaplain or priest be available through last days (Weiner et al., 2013). When asked, parents may describe their belief in the afterlife, discuss heaven as a happy place, and state that everything happens for a reason, whether they like it or not (Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011). But faith also can be ambivalent for the parent of a child who is dying.

Faith helps sustain and provide comfort when parents need to make difficult decisions regarding the life of their child (Meyer et al., 2006). Parents often ask for time to pray and think about what to do, or not do, for their child. Parents describe faith as one of the most helpful tools when facing the death of their child (Robinson et al., 2006). Hexem et al. (2011) reported that parents indicated their trust in God provided feelings of peace and comfort during their child's illness. Faith as a moral compass assisted with decision-making and helped lessen feelings of anger, confusion, and loss of purpose related to the illness.

HOLDING ON TO *HOPE*

Hope is used to help family members cope while facing the child's inevitable demise (Feudtner et al., 2010). Studies have shown a strong correlation between hope and quality of life in adults with cancer (Feuz, 2012). Parents also describe their hopes for their child when discussing medical and end-of-life care decisions with the palliative care team. However, *hopes* for their child and *hope* are not necessarily the same. Hendricks-Ferguson found hope was "a comforting and life-sustaining, reality-based belief that a positive future exists" (2007, p. 390). That future may be a heavenly one, as opposed to an earthly one, but a future remains.

One parent of a child who died stated, "Hope is essential; don't give it up. Even now, I realize it was so important" (Robinson et al., 2006, p. e722). Holding on to hope can be of great comfort and a source of strength. Other parents have echoed the importance of hope as a way to survive emotionally, as well as to try to find meaning in what they were experiencing.

After losing all his children and wealth, the Old Testament man Job asked, "Where then is my hope? Who can see any hope for me?" (Job 15:17, NIV). Many families ask these questions when faced with the death of their child. It is easy to feel that God has forsaken them due to the suffering and grief they are experiencing. Holding fast to hope, yet wrestling with questions, can be comforting to parents. Nurses need to encourage and allow parents to ask and process their difficult questions.

For those who hope in Christ, hope does not end with the child's death. Parents look forward to the day when they will meet their child in heaven (1 Thessalonians 4:17). Hope is a powerful tool to sustain parents in the dark days surrounding the illness and death of their child.

SPIRITUALITY IN THE FACE OF DEATH

Family members repeatedly identify spirituality and religion as important in their decision-making regarding end-of-life issues, finding meaning in the loss of their child, and providing significant social support (Foster, Whitehead, Maybee, & Cullens, 2013). Many parents report prayer, faith in God, and support from clergy as most helpful at their child's end of life, and they appreciate nurses' suggestions for spiritual care (Robinson et al., 2006). Parents of children with life-limiting illnesses may face a crisis of faith, where their whole world is shattered, and the dreams of life for their child have died. It is not unusual for parents to question God. For some, a return to faith and spirituality is difficult. For others, their faith, hope, and spirituality are the anchors that keep them grounded and help them to find meaning through this terrible roller-coaster ride of emotions and grief.

Misunderstandings about the religion of the child and family may occur for healthcare providers (Brierley et al., 2013; McEvoy, 2003). McEvoy (2000) offers the B-E-L-I-E-F mnemonic as one way to facilitate discussions regarding spiritual beliefs of the family: "B-belief system, E-ethics or values, L-lifestyle, I-involvement in a spiritual community, E-education, F-future events" (p. 40). This system allows the nurse to open crucial conversations in a nonthreatening manner and opens a door for families to begin discussing and processing their beliefs and values in an end-of-life situation with their child.

Loss of a child is devastating to the family, and families facing the loss of a child may experience a crisis of faith. The majority of people facing death want to have their religious beliefs acknowledged by the healthcare team. However, only about half of pediatricians choose to discuss religion with children and families (Rosenbaum et al., 2011). This leaves a gap in providing for the spiritual health of the child and family. But the variety of needs displayed by families can make spiritual care difficult (Foster et al., 2013). Each family is a unique entity, and a number of factors are involved in ensuring that families receive needed care. These include institutional roles, norms, available resources, involvement of personal clergy, added needs for spiritual support when their clergy is unavailable, and the ability to practice religion freely with their child. These, in combination with other individualized practices, provide families with the hope, faith, and strength they need to survive this family crisis.

Our ability to understand and provide spiritual support to parents and children with a life-limiting illness makes getting a detailed spiritual assessment crucial. It is only through assessing the spiritual needs of the child and family that healthcare providers can begin to understand spiritual needs. The spiritual assessment helps in the recognition of individual differences within, and between, others of a similar religion or faith. The assessment provides vital information to help ensure that children and families receive the type of care needed to help them.

Nurses frequently are the ones to whom parents bring their questions about coping, finding meaning in what is happening, and revealing spiritual concerns (Foster, Bell, & Gilmer, 2012). This enables nurses to make appropriate referrals and inform other members of the healthcare team about the spiritual struggles the family is experiencing. Spiritual distress should be addressed immediately to prevent breaches in communication and help with faith crises.

COMMUNICATING ABOUT DYING

It is imperative that parents participate in end-of-life decision-making for their child, including the decision of when and what to tell the child, how to tell him or her, and how to spiritually prepare themselves and the child for the child's death. How can nurses help prepare families for the types of discussions needed when children are facing the end of life? How do we support families through the nightmare of losing a child?

Studies indicate that children with chronic illness have a sense when they are dying and want to ask questions about what is going to happen to them, and where they go when they die (Linebarger, Sahler, & Egan, 2009). However, children do not ask their parents because they don't want them to be sad. Conversely, parents may not talk with their child, fearing he or she will be frightened (Hendricks-Ferguson, 2007). These unfortunate misconceptions often interfere with the communication needed to make the end of life easier for both parents and children.

In a study with 449 parents participating, Swedish researchers explored the question of whether or not parents should discuss death with their terminally ill child. Of those, 147 parents had discussed death with their child and had no regrets. Another 258 parents chose not to discuss death with their child, and 69 of those parents (27%) regretted that decision. However, there was no discussion about how, and when, to broach the subject of dying with the child (Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004). Multiple resources for discussing death with children can be found in the Web Resources at the end of this article.

Another body of literature discusses the importance of allowing children to participate in decisions about their care (Bluebond-Langner, Belasco, & DeMesquita Wander, 2010). It is imperative that we find a way to support families as they begin to have these crucial conversations with their child. Not all parents are able to recognize the need to begin such conversations, and if they do, they seldom know where to begin discussing this delicate information with their children.

Little is said about the factors leading up to the discussion of dying to help parents know when to approach this topic. Crisp (in press) describes how she used a near-death experience to broach dying with her teenage daughter with medically complex issues. Her child described going to heaven and seeing her grandfather, older sister, and the dog before being told to return to her body. Discussions between mother and daughter continue, so that the child is unafraid of dying and knows it will be okay when the time comes for her to leave.

Numerous studies reveal that spirituality is important to families who have a child with a life-limiting illness.

LOOK AT THE ANGELS!

Children who have been resuscitated may describe a near-death experience (NDE) upon awakening. Descriptions often include details about who the child saw, what they did, what heaven looks like, and how they came back in their beds (Crisp, in press; Curtis, 2012). Such experiences can provide great comfort to parents (Ethier, 2007; Morse, 1994; Wills-Brandon, 2000). The NDEs provide knowledge that the child knows where he/she is going, who will meet him/her there, and that the child is comfortable with dying.

Death-related sensory experiences (DRSEs) or deathbed visions, also called veridical hallucinations, differ from NDEs in that DRSEs are experienced by children undergoing the dying process. Children have described a deceased family member or heavenly messenger who communicates with them and appears to help them with the transition to death (Ethier, 2005; Rushing, 2012). Families report loved ones' visions of angels, previously passed family members, or other religious figures shortly before leaving his/her earthly body. This phenomenon is familiar to families who recall a child saying, "Look at the angels. They are so pretty!" just before taking a last breath (Mazzarino-Willett, 2010; Rushing). Such visions are a phenomenon that has been described by children and adults of many faiths, religions, cultures, races, and ethnicities (Atwater, 2002; Curtis, 2012; Wills-Brandon, 2000).

These related experiences seem to work for one purpose—to assist the child and family in the transition from life to death. It is powerful, not only for the child, but also for caregivers during this difficult, but often peaceful, time (Mazzarino-Willett, 2010). These intense spiritual experiences can open a door to discussing death with the child and parents. Psalm 23 is well known

Heaven Is Purple, Yellow, and Green

End of life discussions are difficult for families who have a loved one who is dying. There is no easy way to broach the subject. But when the dying loved one is a child, conversations and emotions are compounded. As the parent of two medically fragile children, I have survived the premature death of my older daughter and am preparing my younger daughter for her life's end, following three near death experiences. My goal is keeping this wonderful child from being afraid of her death, giving her permission to go when the time comes, and reassuring her that I will be okay and will always love her, even when she is no longer with me. Together, we find peace, knowing we will see each other again someday.

Meishy is my 17-year-old who suffered a cervical spinal cord injury at birth, resulting in severe disability. Additionally, at only a few months old, she experienced a life-threatening event causing cerebral palsy and a significant cognitive disability. Meishy has been completely ventilator-dependent for the past 12 years.

Meishy is wise beyond her years. She is unable to speak, due to dysarthria from cerebral palsy. She uses sloppy signs to convey her messages but is emphatic in telling me she has been to heaven to visit Jesus, Grandpa, her older sister, Stacie, and her dog. She finds peace having met this familiar group who will guide her to heaven when the time is right.

A few years ago, my daughter's heart stopped beating and required resuscitation. Days later, I asked her if she had visitors while she was gone. She shook her head. When I asked who those visitors were, she definitively signed "Grandpa" and "Jesus."

A few days after that conversation, I asked her, "Meishy, what color is heaven?" She distinctly signed "purple, yellow, and green." She also signed that she had played with her dog and her sister during her heavenly visit. She smiled and danced in bed to show she is happy. On the anniversary of her sister's death, she again stopped breathing, and once again I was able to revive her.

Periodically, we have discussed her visits to heaven. I remind her that she can go when the time is right and that I will be okay. These discussions have been some of the most difficult of my life, but I find great peace in knowing that Meishy has no fear.

For now, I embrace each day my daughter is with me. I think my greatest achievement as a mom is in knowing that my child is not afraid to die. I hold fast to God's promise that, "I can do all things through him who strengthens me" (Philippians 4:13, ESV). This promise will sustain me in those early days without her. I also can look forward to the day when we are all together again. And, I have it on good authority that heaven is purple, yellow, and green.

and states in part, "Even though I walk through the valley of the shadow of death, I will fear no evil, for you are with me; your rod and your staff, they comfort me" (Psalm 23:4, NIV).

EFFECTIVE COMMUNICATION

Effective communication between parents and children can be greatly enhanced through effective communication between the healthcare team and the family. Parents have reported healthcare providers "side-stepping" or "hem-hawing" around vital information needed by the family (Meert et al., 2008). Parents want to be told the truth in words they understand. Too often, healthcare members use words the family has difficulty understanding, and families experience being talked to in a way that may not seem supportive or caring.

Sadly, families have reported that healthcare systems are not always sensitive to their plight (Aschenbrenner et al., 2012). Providers who are oblivious to parents' needs and desires are not helpful. Some professionals may not understand the importance of the family's need to continue relationships with the child at the end of life. Families want to remain a part of the life of their child and may do so with presence, words, or symbols. They need adequate support to do so effectively, and that support can be lacking. Nurses are crucial in providing sensitive, engaging support to the child and family.

Many children with long-term illnesses have frequent hospital admissions, and the family and healthcare providers become close. Providers can have a difficult time when a child who is dying asks them questions. How can we expect the parents of these children to face discussions about dying when healthcare professionals find these discussions difficult, let alone speak with family members (Horridge, 2012)? Many healthcare workers employ the same spiritual survival techniques as parents, turning to their beliefs for comfort and peace.

One place to start with effective communication is to ensure children and families are referred to an appropriate palliative care program early in the course of illness. The overall purpose of pediatric palliative care is to "add life to the child's years, not simply years to the child's life" (American Academy of Pediatrics, as cited in Field & Behrman, 2003, p. 134). By enrolling children and families in appropriate programs, this goal can be accomplished. This offers the assurance that they will have support throughout the end-of-life process. Pain management, comfort, and spiritual support are part of this vital program.

An assessment of parental understanding of the child's illness and prognosis offers insight on what communication is needed. Combine your assessment of parental understanding with spiritual assessment, and families may be more willing to share vital information with caregivers. These assessments suggest emotional spaces where healthcare workers can begin delicate communication about end-of-life issues. It is imperative to assess sensitive issues such as, "Would you feel more comfortable having your child in the hospital or at home?" Not all families go through the process of acceptance at the same time, so it is essential to have an idea of where families are before proceeding. Developing a plan for what the child and parents want done at end of life is invaluable, especially for emergency care. Helping parents decide what interventions to use, such as facial oxygen, bag and mask ventilation, and so forth, can seem less negative than a Do Not Resuscitate all-or-nothing order (Wolff, Browne, & Whitehouse, 2011).

Communication needs to be continual and informative. Communication between and within the appropriate palliative care disciplines, and between and within families, can help the bereavement process and make families feel more a part of the team. It is essential to meet parents at their level of communication so that they feel a part of the team and that no information is being withheld from them. Tools such as the BELIEF model (McEvoy, 2000) can be used if there is difficulty in getting conversations started. In addition, parents who are allowed to discuss their faith and hope have much better outcomes than those who do not (Limbo & Kobler, 2014).

Include the child in decision-making discussions, if developmentally appropriate. We can learn a lot by listening to our patients. A child may reach a comfort level with death and be ready to transition much earlier than other family members. However, the child may not feel comfortable telling the parents this, for fear of inflicting more pain on them. This is a deeply held secret that will not be shared without appropriate encouragement.

Having the right pastoral care available to the family is quite beneficial during difficult crossroads in the child's journey through a life-threatening illness. Allow the family to guide you on how to best meet their spiritual needs and offer to contact spiritual advisors. Nurses, hospital chaplains, and other clergy should freely offer spiritual care, nurture acceptance of parents' spiritual perspectives, and collaborate to give spiritual support to families and children.

CARE FOR PROVIDERS

Unfortunately, some healthcare professionals feel like they are a failure if the patient dies (Morgan, 2009). It is useful for nurses to do a self-inventory of their attitudes and beliefs about the care of children with life-limiting illness. Nurses need to explore their feelings about caring for children who are dying and realize it is healthy to discuss and process their emotions. Christians believe that death is not the end; it is a new beginning. "In my Father's house are many rooms; if it were not so, I would have told you. I am going there to prepare a place for you" (John 14:2, NIV). Believing this, we can lean into new beginnings rather than dwelling on the loss, while still providing support and comfort to grieving parents.

It also is important that organizations provide adequate care for staff members taking care of dying children. Nurses report an intense sadness that accompanies continually caring for children with life-limiting illness (Morgan, 2009). Sometimes, nurses get so bogged down taking care of others that they forget to care for ourselves. It is imperative to provide space, such as a chapel or quiet room, for staff members to go and regroup. Commemorating a

Encourage and allow parents to ask and process their difficult questions.

Agencja Fotograficzna Caro / Alamy Stock Photo

child's life through cards to the family, a memory book or poster, debriefing together, or going to a child's memorial service can help nurses deal with grief (Limbo & Kobler, 2014). God's Word offers encouragement to Christian nurses: "Be strong and courageous, and do the work. Do not be afraid or discouraged, for the Lord God, my God, is with you" (1 Chronicles 28:20, NIV). God offers strength to continue, as we ask him for help.

CONCLUSION

The journey is difficult for children with life-limiting illness, their families, and their healthcare providers. Learning how to support children's and families' faith, hope, and spiritual needs can help make the journey more passable. More work is needed to help families communicate more effectively with their providers and have crucial conversations with their children about dying. Further research is needed to explore what types of faith, hope, and spiritual supports are needed by children to help them prepare for their transition from this world to the next.

Pediatric palliative care nurses provide care in an environment with complex issues. Nurses who are strong in their faith can be of great comfort to families as their child nears the end of life. Often, all that is needed is a hand to hold, a compassionate touch on the shoulder, a hug, or someone to cry with as families work through the next stage of their child's transition. Words, gestures, and appropriate touch from nurses are vitally important to families when their child is close to death. Being fully present with the child and family assures them they are not alone.

As Christian nurses, we long for the day when death is no more.

"He will wipe every tear from their eyes. There will be no more death or mourning or crying or pain, for the old order of things has passed away" Revelation 21:4 (NIV).

Web Resources

- Bereaved Parents of the USA—http://bereavedparentsusa.org/
- Children's Cancer—http://www.childrenscancer.org
- End-of-Life Nursing Education Consortium (ELNEC)—http://www.aacn.nche.edu/elnec
- Hospice & Palliative Nurses Association—http://hpna.advancingexpertcare.org/
- International Children's Palliative Care Network—http://www.icpcn.org/
- MISS Foundation—http://www.missfoundation.org/
- *My Wishes* Pediatric Version—https://agingwithdignity.org/five-wishes/pediatric
- Talking with Children about Death—http://www.hospicenet.org/html/talking.html
- The Compassionate Friends—http://www.compassionatefriends.org/home.aspx
- The Grief Toolbox—http://thegrieftoolbox.com/

Aschenbrenner, A. P., Winters, J. M., & Belknap, R. A. (2012). Integrative review: Parent perspectives on care of their child at the end of life. *Journal of Pediatric Nursing, 27*(5), 514–522.

Atwater, P. M. H. (2002). Near-death experience in children. *The Journal of Religion and Psychical Research, 25*(1), 26–29.

Bluebond-Langner, M., Belasco, J. B., & DeMesquita Wander, M. (2010). "I want to live, until I don't want to live anymore": Involving children with life-threatening and life-shortening illnesses in decision making about care and treatment. *Nursing Clinics of North America, 45*(3), 329–343. doi:10.1016/j.cnur.2010.03.004

Brierley, J., Linthicum, J., & Petros, A. (2013). Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children? *Journal of Medical Ethics, 39*(9), 573–577. doi:10.1136/medethics-2011-100104

Curtis, L. (2012). Deathbed visions: Social Workers' experiences, perspectives, therapeutic responses, and direction for practice. *Master of Social Work Clinical Research Papers, St. Catherine University*. Retrieved from http://sophia.stkate.edu/msw_papers/17

Ethier, A. M. (2005). Death-related sensory experiences. *Journal of Pediatric Oncology Nursing, 22*(2), 104–111.

Ethier, A. M. (2007). *Exploring parents' memories of their child's death related sensory experiences as a dimension of grieving.* Retrieved from Digital Commons at the Texas Medical Center (AA13281710).

Feudtner, C., Carroll, K. W., Hexem, K. R., Silberman, J., Kang, T. I., & Kazak, A. E. (2010). Parental hopeful patterns of thinking, emotions, and pediatric palliative care decision making: A prospective cohort study. *Archives of Pediatric & Adolescent Medicine, 164*(9), 831–839.

Feuz, C. (2012). Hoping for the best while preparing for the worst. A literature review of the role of hope in palliative cancer patients. *Journal of Medical Imaging and Radiation, Sciences, 21*(3), 168–174.

Field, M. J., & Behrman, R. E. (Eds.). (2003). *When children die: Improving palliative and end-of-life care for children and their families.* Washington, DC: National Academies.

Foster, T. L., Bell, C. J., & Gilmer, M. J. (2012). Symptom management of spiritual suffering in pediatric palliative care. *Journal of Hospice & Palliative Care Nursing, 14*(2), 109–115.

Foster, M. J., Whitehead, L., Maybee, P., & Cullens, V. (2013). The parents', hospitalized child's, and health care providers' perceptions and experiences of Family Centered Care within a pediatric critical care setting: A metasynthesis of qualitative research. *Journal of Family Nursing, 19*(4), 431–468. doi:10.1177/1074840713496317

Hendricks-Ferguson, V. L. (2007). Parental perspectives of initial end-of-life care communication. *International Journal of Palliative Nursing, 13*(11), 522–531.

Hexem, K. R., Mollen, C. J., Carroll, K., Lanctot, D. A., & Feudtner, C. (2011). How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *Journal of Palliative Medicine, 14*(1), 39–44. doi:10.1089/jpm.2010.0256

Horridge, K. A. (2012). Dying, death, disabled children and young people: How might we be better prepared? *Child: Care, Health and Development, 38*(1), 3–5. doi:10.1111/j.1365-2214.2011.01268.x

Knapp, C., Madden, V., Wang, H., Curtis, C., Sloyer, P., & Shenkman, E. (2011). Spirituality of parents of children in palliative care. *Journal of Palliative Medicine, 14*(4), 437–443. doi:10/1089/jpm.2010.0387

Kreicbergs, U., Valdimarsdóttir, U., Onelöv, E., Henter, J. I., & Steineck, G. (2004). Talking about death with children who have severe malignant disease. *The New England Journal of Medicine, 351*(12), 1175–1186.

Limbo, R., & Kobler, K. (2014). *Meaningful moments: Ritual and reflection when a child dies.* Lacrosse, WI: Resolve Through Sharing.

Linebarger, J. S., Sahler, O. J., & Egan, K. A. (2009). Coping with death. *Pediatrics in Review, 30*(9), 350–356. doi:10.1542/pir.30-9-350

Mazzarino-Willett, A. (2010). Deathbed phenomena: Its role in peaceful death and terminal restlessness. *American Journal of Hospice & Palliative Medicine, 27*(2), 127–133. doi:10.1177/1049909109347328

McEvoy, M. (2000). An added dimension to the pediatric health maintenance visit: The spiritual history. *Journal of Pediatric Health Care, 14*(5), 216–220.

McEvoy, M. (2003). Culture & spirituality as an integrated concept in pediatric care. *MCN. The American Journal of Maternal Child Nursing, 28*(1), 39–43.

Meert, K. L., Eggly, S, Pollack, M., Anand, K. J., Zimmerman, J., Carcillo, J, ..., National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network. (2008). Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatric Critical Care Medicine, 9*(1), 2–7. doi:10.1097/01.PCC.0000298644.13882.88

Meyer, E. C., Ritholz, M. D., Burns, J. P., & Truog, R. D. (2006). Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations. *Pediatrics, 117*(3), 649–657. doi:10.1542/peds.2005-0144

Morgan, D. (2009). Caring for dying children: Assessing the needs of the pediatric palliative care nurse. *Pediatric Nursing, 35*(2), 86–90.

Morse, M. L. (1994). Near death experiences and death-related visions in children: Implications for the clinician. *Current Problems in Pediatrics, 24*(2), 55–83.

Murphy, S. L., Xu, J, & Kochanek, K. D. (2013). Deaths: Final data for 2010. *National Vital Statistics Report, 61*(4), Tables 10 & 11. Retrieved from http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_04.pdf

Robinson, M. R., Thiel, M. M., Backus, M. M., & Meyer, E. C. (2006). Matters of spirituality at the end of life in the pediatric intensive care unit. *Pediatrics, 118*(3), e719–e729. doi:10.1542/peds.2005-2298

Rosenbaum, J. L., Smith, J. R., & Zollfrank, R. (2011). Neonatal end-of-life spiritual support care. *The Journal of Perinatal and Neonatal Nursing, 25*(1), 61–69. doi:10.1097/JPN.0b013e318209e1d2

Rushing, D. S. (2012). "Am I going to die, Aunt Deborah?" *Journal of Christian Nursing, 29*(2), 113–115. doi:10.1097/CNJ.0b013e3182470b8e

Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative & Supportive Care, 11*(1), 47–67.

Wills-Brandon. (2000). *One last hug before I go: The mystery and meaning of deathbed visions.* Deerfield Beach, FL: Health Communications.

Wolff, A., Browne, J., & Whitehouse, W. P. (2011). Personal resuscitation plans and end of life planning for children with disability and life-limiting/life-threatening conditions. *Archives of Disease in Childhood. Education and Practice Edition, 96*(2), 42–48. doi:10.1136/adc.2010.185272

Instructions for Taking the CE Test Online

- Read the article. The test for this CE activity can be taken online at www.NursingCenter.com/CE/CNJ. Find the test under the article title. Tests can no longer be mailed or faxed. You will need to create a username and password and log in to your free personal CE Planner account before taking online tests. Your planner will keep track of all your Lippincott Williams & Wilkins online CE activities for you.
- There is only one correct answer for each question. A passing score for this test is 13 correct answers. If you pass, you can print your certificate of earned contact hours and access the answer key. If you fail, you have the option of taking the test again at no additional cost.
- This CE test also is available for viewing at www.journalofchristiannursing.com in the table of contents for this issue under CE Test Preview
- Visit www.nursingcenter.com for other CE activities and your personalized CE planner tool.
- For questions, contact Lippincott Williams & Wilkins: 1-800-787-8985.

Registration Deadline: March 31, 2018

Disclosure Statement: The authors and planners have disclosed that they have no financial relationships related to this article.

Provider Accreditation:

Lippincott Williams & Wilkins, publisher of *Journal of Christian Nursing,* will award 2.5 contact hours for this continuing nursing education activity.

Lippincott Williams & Wilkins is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

This activity is also provider-approved by the California Board of Registered Nursing, Provider Number CEP 11749 for 2.5 contact hours. Lippincott Williams & Wilkins is also an approved provider of continuing nursing education by the District of Columbia, Georgia, and Florida, CE Broker #50-1223. Your certificate is valid in all states.

Payment and Discounts:

- The registration fee for this test is $24.95 for nonmembers; $17.95 for NCF members.

CE For more than 30 additional continuing education articles related to pediatric care, go to NursingCenter.com/CEConnection and search "pediatrics."