Welcome to the 48th issue of the ChiPPS E-Journal. This issue of our E-Journal offers a collection of articles that explore selected issues related to spiritual care of children and their families. We recognize that offering spiritual care is a central dimension in pediatric palliative and hospice care. As well, we appreciate that such spiritual care is often offered in many different ways. A single issue on this subject will not do full justice to this subject area, but we hope that the articles in this issue will spur increased awareness and discussion of these subjects. We welcome communications from anyone who has more to offer on these subjects.

This E-Journal is produced by ChiPPS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s E-Journal Work Group, chaired by Christy Torkildson. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-Journal Work Group, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Please contact Christy at ctorkildson@mail.cho.org or christytork@gmail.com or Ann at ann@here4U.net

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Issue #48: Spiritual Care of Children and Their Families
(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

*Suspended* p. 5
Kristin Wickless, RN, BSN
It seems appropriate to begin this issue with a poem by a nurse who works in a children’s hospital NICU and who is a mother to a palliative care patient. Her poem reminds us of her “terror and the child in the bed on whose next breath the fate of the world depends.”

*A Mother’s Perspective on Palliative Spiritual Care: What Helped, What is Still Needed* p. 6
Dannell Shu
In this article, the author writes as the mother of a child who needed pediatric palliative care during the entire seven years of his life. She notes that “The spiritual care we received fluctuated greatly throughout these seven years” and then describes seven beneficial services they did receive along with two services they never found.

*“Existential Distress”: Alleviating a Teen’s Psychological Pain at the End of Life* p. 9
Ann Fitzsimons, BS, MBA
Our second article in this issue turns the focus to a teenager and the interdisciplinary team that was caring for him by telling the “story of how a very caring and intuitive inter-disciplinary team alleviated the ‘existential suffering’ of a teen age boy who was facing his impending death by watching and listening to what he was saying, and not saying, at the end of his life.”

*The Role of Hope in Pediatric Palliative Care* p. 12
Suzanne Toce, MD
While acknowledging that it may seem counterintuitive to talk about hope in the context of pediatric palliative and hospice care, this thoughtful review of the issues involved rightly concludes that “hope is an important part of healing for children with life-limiting conditions and their families. Hope(s) change over time and significantly contributes to coping and decision-making. There are communication strategies to help clinicians elicit appropriate hopes, support the child and family, and enhance decision-making. I hope that this review has encouraged and supported your inclusion of hope as part of your management strategies in the pediatric palliative care setting.”

*The Role of Spirituality in Caring for Children and Their Families* p. 16
The Reverend Harlan E. Ratmeyer, D. Min.
The main thrust of this article is to argue that “especially in long-term relationships in palliative care, the spirituality of the staff becomes more and more visible. How we perceive our job or vocation, how we communicate awe and wonder gradually emerge for children and families to view. Thus the challenge in pediatric palliative care is not only to bring in a chaplain and address a child’s concerns, but to be aware that each one of us brings aspects of spirituality to our work.”

*A Village of Care* p. 18
M. Karen Ballard, MCM, BCC
In this article, an experienced pediatric palliative care chaplain argues that, “Spiritual care is not so much the application of a particular discipline as it is an organic way of being in a relationship with families. It is approaching a family’s life and how they experience and express meaning with reverence for their choices and ways of being on their particular journey. It is listening and affirming their approach, but also offering alternatives that may be beneficial.” She concludes that, “It is not about what we might do, but rather how we might be present to create a safe space for reverence and silence and pondering words that cultivate the sacred moments that we share with these amazing patients and families.”
Supportive Care: Be the Door
Karen Wilson-Kedro, OT
This article describes an occupational therapist's role in providing supportive care and, in particular, what she learned from her interactions with “a teenage girl who had a self-inflicted injury,” a girl who was coping with multiple life challenges in addition to the fact that she was “a girl with a significantly injured face, who could not talk, and had uncertain vision and cognitive processing.”

Who Ya Gonna Call?
Rev. Becky Johnson, MDiv, BCC
Case examples in this article describe the work of an experienced pediatric chaplain. She points out that one important way to support youngsters and their families in this role is to ask: “How can we best honor your family and spiritual traditions at this time?” Her conclusion: “I am truly blessed to serve as a pediatric chaplain. So, who you gonna call? How about calling the chaplain…it is our job to assess, discern, and provide spiritual support to people of all faiths and even people with no faith tradition.”

Using Art to Facilitate Spiritual Exploration
Rev. Kirstin Springmeyer, MDiv, BCC
In this article, the author uses three case examples and three different types of art tools to advocate for the value of “using art as a means for spiritual and religious reflection is helping to engage the patient and family to explore” issues related to where is God in all this. She concludes: “Art contributes to a patient/family's imagination to explore and dive deeply into sacred traditions. As a palliative care chaplain I can support them in discovering new, personal, even healing encounters with God a Higher Power as they see it.”

Religion, Spirituality, and Pediatric Patients and Families: Research, Assessment, and Care
Melissa Kurtz, MSN, MA, RN, PhDc, & Ashley Hurst, JD, MDiv, MA
According to the authors, “This article provides an overview of current research related to religion and spirituality for pediatric patients and families, describes the available spiritual assessment tools and care process for pediatric patients and families, and suggests areas of future research that could help inform and strengthen healthcare teams’ provision of spiritual care to children and families.”

Nurses and Spiritual Care of Seriously-Ill Children and Their Families
Betty R. Ferrell, RN, PhD, MA, FAAN, FPCN, CHPN
This article summarizes two recent articles on the spiritual care needs of seriously-ill children and their families, and nurses’ experiences in spiritual communication with seriously-ill children.

Trends in Pediatric Palliative Care Citation List, 2017, #6
Commentary by Dr. Adam Rapoport
This citation list is generated monthly by PedPalASCNET to collect new articles in pediatric palliative care research. To see past citation lists and expert commentaries visit their blog. (Note: We include this bibliography of new articles in PPC as an additional service to readers.)
ADDITIONAL NOTES

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at www.nhpco.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.

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SUSPENDED
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There are places
too wild and nomadic to name
that break us down.

They slam us to our knees.
They rip sobs from our bodies.

Fear hungers.
It is not sated.
Fierce and furious - suddenly it is all that is left.
Ravenous, it devours every thought, every heartbeat, every breath.

The careful frowns on the doctors' faces.
Her body still but for moans of pain.
The incessant beeping on which the universe hangs.

I am consumed.

There is nothing left.
Only my terror and the child in the bed on whose next breath the fate of the world depends.
A MOTHER’S PERSPECTIVE ON PALLIATIVE SPIRITUAL CARE: 
WHAT HELPED, WHAT IS STILL NEEDED

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My son, Levi, was born with severe brain damage. Due to the complex medical conditions reverberating from his brain damage, Levi needed palliative care support his whole life. In seven years, this support allowed Levi to live happily at home with our family, ER visits were minimal (4 times a year at most), hospitalizations were only 3 weeks NICU at birth and 2 weeks PICU at age 3, all major illnesses and his end of life were supported at home. As a result of so few hospitalizations and limited clinic visits, the majority of our palliative support was community based/in home.

The spiritual care we received fluctuated greatly throughout these seven years. As programs changed, so did our needs as a family. We looked to both hospital-based programs that provided in-home services, as well as community-based programs to help us meet the spiritual needs of our family. Here is a summary of the impact of these services plus two services we needed but never found.

1. Chaplain
When initially approached by the Chaplain we were encouraged to “ask for what we need and to know this support could take any form we needed.” Having just been weeks away from our son’s birth, tidal wave of diagnoses, deep in the trenches of learning how to care for his complex needs, we were clueless on how to respond. Even as people of faith, connected to a faith community, and having served in pastoral leadership, we were still clueless. We already had people praying for our family, a CaringBridge site, and meals were still being dropped off. What more could be done? It took years for us to discover our response: a need to have conversations, away from our home, about the inherent spiritual nature and challenges of having a child on palliative care. These ‘coffee shop conversations’ gave us the insight, support, and thoughtful questions to return home with greater spiritual perspective. The ability to be heard and seen by someone with an open heart and no “agenda” was a tremendous gift. By example we learned more about how to “hold the space” and bring that home to our child.

2. Nurses in the Know
In every version of palliative care my son received, our nurses were the most frequent point of contact. They came to intimately know our family, home life, and complexities of our child. Nurses who took the time to learn about our spiritual beliefs were able to support the faith-life of our family. These same nurses got to know me as a person, were willing to see my spiritual distress, and open the door to talk about it. With as many doctors and nurses I saw over my son’s seven years, these moments with our palliative nurse were a rare gift.

3. Music Therapist: bringing forth the unseen
There was always an acknowledgement of the sacredness of this moment, when the music therapist visited. Whether music therapy was being used to support comfort, reduce anxiety and pain, create meaningful sibling interactions, bring joy, provide neurological ease during difficult moments (ex: position transfers), engage my child in music-making, or pre/post medical procedures, the value of my child as a whole-person was always front and center. The best music therapists were spiritually attuned and understood the spiritual implications of their work. These sessions became times for us to slow down as a family and re-center ourselves on the easily unseen spiritual aspects of loving and caring for one another.

4. Creating a Plan of Care: a spiritual safety net
Within the first weeks of transitioning from the NICU to home, our palliative team guided us through a conversation to learn about our values and beliefs as parents, educating us on the realities of emergency interventions for our son, and helping us translate both into medical decisions with a plan of care. Over
the years, this plan became a spiritual safety net for us. When faced with an emergency or significant downturn in my child’s health, the plan kept everyone on the same page with how to proceed. It also protected my husband and me from having to work through difficult medical decisions in the midst of increased trauma. As a result we had more energy to be spiritually present with our child and each other in these moments. Over the years I have witnessed fellow parents slide quickly down a spiritual spiral when an emergency arises and the work has not yet been done to create a plan.

5. Sibling Playmate: who is coming for me today?
At three years of age, my younger son would wake up every morning and ask “who is coming for me today?” Having a brother with medical complexities means many, many people visit your home, at all hours, for the purpose of supporting your brother. If you are lucky, someone will stop and connect with you for a few moments, maybe even play with you. Through a community-based palliative program we were able to have a volunteer come once a week for the sole purpose of playing with my younger son. These visits were golden to him. They boosted his self-esteem and gave him a place of value in the sea of visitors.

6. Meeting Fellow Parents: being understood
HIPPA has made it more difficult for families with similar children to find each other, particularly when the umbrella diagnosis doesn’t have an organization to reach out to. Yet when we parents find each other, we generate an enormous amount of spiritual support for one another, even when we come from different faith traditions. We are finally understood without having to explain the “what” and “whys” about our child. Children with medical complexities in need of palliative care are a unique group whose parents are in serious need of community. Isolation becomes the norm. Our community-based palliative program supported family respite weekends at Faith’s Lodge, where we met families like ours and formed lifelong friendships. Non-palliative programs hosted family picnics, mom’s retreats, and special events as a way of connecting families.

7. Marriage Counseling: undoing aloneness
Two years ago our community-based palliative program began to offer monthly small group marriage counseling sessions to parents whose children are medically complex. In these sessions we met with a marriage and family therapist to focus on the unique challenges we face as we work to undo aloneness, repair our marriages, and support relational attachment, while recognizing and supporting grief. Our particular therapist gives direct attention to the spiritual needs within marriage and the particular challenges we face with children who have life-limiting conditions. This has been life changing for every couple.

There are two aspects of spiritual support we longed for but never received, both of which could be supported by hospital or community-based palliative programs.

1. Rituals for Tending to my Child’s Soul
In addition to being medically complex, my son was also nonverbal, deafblind, and had limited physical movements. Meanwhile his heart was huge and his soul deeply attentive. Within the swirl of tending to his medical, social, therapeutic, and educational needs, we often were at a loss for how to engage our son within our faith tradition. Gathering with our faith community was inconsistent at best due to his medical challenges.

The chaplain, nurses, music therapists, and child-life specialists could each support a family in exploring ideas on how to find meeting points between their child and faith tradition, by noticing a family’s faith practices and asking open-ended questions to invite a parent to think inclusively about their child. Have you considered taking time to pray with your son and allowing time/silence for him to pray? I notice you are a family that sings (song of faith), how could your child uniquely participate? As you prepare for (faith holiday) have you considered ideas for how your child will experience this holiday? What would make the holiday special to him? Encouragement can be provided for families to find ways to engage their child in faith traditions: modified rituals to support a child’s abilities, specific inclusion in faith holidays, finding accessible places of worship. Tending to the soul of their child will spiritually nourish the parent and the whole family.

Children’s Project on Palliative/Hospice Services
CHPES serves as the Pediatric Advisory Council for the National Hospice and Palliative Care Organization.
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2. End-of-Life Planning: a second safety net
Our son was born with a life-limiting condition. Doctors anticipated weeks to months as his initial lifespan. The older he got the more the unknowns of death loomed. When my son’s friend with medical complexities died unexpectedly, I witnessed the parents become overwhelmed with shock and grief and then were asked to make critical end-of-life decisions. Soon after that, grief easily gets compounded by guilt, spiritual trauma, and questioning if you did right by your child.

End-of-life planning needs to go hand in hand with the creation of a care plan. As difficult as these conversations are for parents, the compounded grief of not having had the opportunity to plan is worse. Palliative teams are skilled at helping families translate their values into medical decisions. These same skills can be developed for end-of-life planning. We enlisted the help of a home funeral guide to create a plan for my child’s end of life, after-death care, and memorial preparations. Death doulas are another resource. Waiting until a child is on hospice to start these conversations is too late. For parents who have worked long and hard to support their child’s life, there is an enormous amount of spiritual stress in making the shift onto hospice and supporting their child’s transition into death. Having an end-of-life plan in place provides a critical safety net for parents and providers alike.

There is an enormous benefit when every member of the palliative care team is engaged in spiritual care. Everyday moments become transformable and spiritual distress is alleviated. The process of translating one’s values into medical decisions for the creation of plans of care for emergencies and end of life, allows families to thoughtfully prepare. Without such plans spiritual pain increases as parents try to navigate the complexities of these decisions and their relationships while in crisis. Undoing aloneness for the whole family is a critical way of providing spiritual support and longevity. There is little time to work on repairing relationships when parents have to give their total attention to the complex medical needs of their children. More attention needs to be given to the spiritual experience of the child, particularly when he or she is not able to speak about this on his or her own. Families need support and encouragement to engage their child in their faith tradition in meaningful ways. Tending to the spiritual needs of families takes time, thoughtfulness, and a willingness to be present with people in their spiritual distress. This happens best when members of the palliative team are invested in tending to their own spiritual needs.

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“EXISTENTIAL DISTRESS”:
ALLEVIATING A TEEN’S PSYCHOLOGICAL PAIN AT THE END OF LIFE

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In hospice, we talk about caring for children and families, in body, mind, and spirit. We have clinicians and clinical tools to help care for, or even cure, these children—surgeries, treatments, medicines, and more. Child life specialists and social workers try to care for their minds, and spiritual caregivers and chaplains (if there are any involved), are the caregivers for the spirit of the child. There are pain management teams who are called in to control and help manage the child’s physical pain, but what about a child’s emotional pain, or something that has been coined, “existential distress”? Which member(s) of the team can help with THAT kind of pain when a child is dying?

While not directly relatable, a recently released study published in the New England Journal of Medicine on assisted suicide sheds some interesting insights on how impactful and powerful psychological, or existential suffering, can be at the end of life for adults. There is no reason, in my mind, to think that this is not also true for some children, teens, and young adults who are dying. In the Canadian study, for adult patients facing an incurable disease like cancer or a neurological disorder like Lou Gehrig’s disease, they wanted to choose death over life more because of the psychological suffering they were experiencing than anything to do with the physical pain associated with their declining condition. They were losing their autonomy and their identities to these diseases, and that is not how they wanted to live out whatever time they had left. There are lessons in this research for our work with children.

Here, now, is the story of how a very caring and intuitive inter-disciplinary team alleviated the “existential suffering” of a teen age boy who was facing his impending death by watching and listening to what he was saying, and not saying, at the end of his life. They recognized his need for autonomy from his parents, and their belief system, and in doing so, freed him from some significant fears impeding his transitioning to a peaceful death.

Jack was a teenager, perhaps 16 or 17, who was dying in the hospital. He had attentive parents who were there by his side as his condition deteriorated. Jack and his parents seemed to have a good, loving relationship. Yet, as the days wore on, Jack started to live two lives—one of a loving, compliant son when his parents were with him and one of an anxious and agitated teen when they were not. An intuitive care team, with Social Work leading the charge, sensed something was going on deep inside Jack as death got closer. However, without ever being able to talk to him alone, they couldn’t really get to the bottom of what was bothering him. In conversations with him while his parents were there, Jack said everything was fine, but the care team wasn’t buying it. The team felt he was putting on a good face for his parents, who were already suffering so much watching him die, and Jack was taking this all in. An IDT meeting was called to discuss a plan to care for ALL of Jack—his body, yes, but especially his mind and spirit. The social worker suggested they try to talk to Jack alone; that it was time to express the team’s concerns to his parents and to make a plea that the social worker would like some alone time with him to see if he would open up about his issues and concerns. The parents agreed and social work approached Jack’s bed with their observations. After some time, they were able to draw Jack out and convince him to open up about what was concerning him. It turned out that he was afraid he was just going out into “nothingness” when he died, and that terrified him. Jack’s parents were Atheists, and he had been raised in that belief system; yet now, as he looked ahead to what was going to happen after he died, he did not want to go out into a dark abyss of “nothingness.” He wanted, no, he needed, to know that there was something else out there for him after death—that he was going somewhere and that it was a good, or even better, place.
After discussing all of this further with Jack, the social worker, and now spiritual care chaplain, asked Jack what would help to alleviate this fear of his and he said, without missing a beat, he wanted to be baptized. He had friends who were raised Christian and he had heard them speak about Heaven and everlasting life in this beautiful place, and he wanted to have that also be true for him when he died. He said he hadn’t been able to discuss this with his parents for fear of hurting their feelings in going against all he had been taught as an Atheist growing up.

The social worker asked Jack if he was okay with them sharing what he had told them with his parents. He was told he could either be part of that conversation, or he didn’t have to be. He opted out of it, still afraid of his parents’ reaction. So the social worker met with his parents and explained all that he had told them. Thankfully, the parents were loving and gracious in deciding to let Jack pursue his own faith path, one that would bring him comfort during and after death.

With the help of the social worker, spiritual care chaplain, and the nursing staff, a priest was then called and when he arrived, Jack was lowered into a therapeutic bathtub to be baptized into the Christian faith. His parents stood witness to this baptism in a loving and supportive way for their son as they granted this one last, but spiritually important, wish for him.

After being baptized, Jack returned to his room and all of the care team noticed an immediate change in his disposition. He was calm, relaxed, and open in his conversations with family and friends. He was able to say his good-byes and create a sacred space for all who loved him, especially his parents, to walk toward his exit from Earth. His life, though ending, had purpose now and he had become accepting of his impending death, as he believed now that there was a new life awaiting him after he left here and that he would be able to fully partake of it. He wasn’t going into black “nothingness.”

Jack died peacefully the next day, with his parents by his side. There was no struggle, only beauty and joy in his transition for those present. He truly believed he was going somewhere amazing and he looked forward to the trip.

While this may seem like a simple story, because of the compassionate actions of Jack’s care team, it resulted in a “good death” for him and his parents. Jack was relieved of the pain that was really hurting him, and attended to the remaining important work he needed to do to say good-bye to those he loved, and who loved him.

This story is shared here to underscore some key points in caring for the spirituality of these children entrusted into our care at the end of life, including:

- How important it is to identify and treat a child’s “existential distress” or “spiritual pain,” if they have any, in addition to their physical pain and symptoms.
- Acknowledging that “existential distress” may be harder to diagnose as the signs of “pain” are not as physically evident. That providing spiritual care to children at the end-of-life oftentimes takes intuition coupled with watching and listening to what children are saying and doing, and also what they are NOT doing/saying. Discernment of how these children are really doing/feeling and what’s really bothering them is as much gut as it is training, so trust your instincts. If something “feels” off or wrong with the child, it probably is.
- Recognizing that a child may have unfinished business to complete before dying that is, or could be, in conflict with what they think their parents may want for them. As a result, navigating this tightrope between the child and parents takes sensitivity and courage to take the child’s wishes on while hopefully not usurping the parents’ role as parents.
- Don’t do this alone—call the team together and compare notes to see if what may be bothering the child is more physical or mental, emotional, and/or spiritual. If anything but physical, use whatever resources are available to help have the conversations with the child and family, and
then use the team/resources to devise a plan to care for their mind and/or spirit.

- Be the best body/mind/spirit companion you can be to these children and their families. Get trained or exposed to tools to help with care of the mind and spirit.

When we work as a team and really silently observe and listen to what a child is telling us, and maybe more importantly, not telling us, spiritual magic can happen that can be life-changing. It was for Jack. May we be this attentive to the spiritual needs of all our pediatric patients at the end of life. Helping these kids come to spiritual resolution or “closure” is a gift for and to them, and their families that will last them all a lifetime.

Reference:


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THE ROLE OF HOPE IN PEDIATRIC PALLIATIVE CARE

HOPE – THE HIDDEN WORD IN HOSPICE

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Talking about hope in the context of pediatric palliative care (PPC) may seem counterintuitive. That perception is a challenge! Healing is enhanced if the child and family are more hopeful. Hope is intrinsic to the child and family’s coping and decision-making and appropriate hopes should be sought and encouraged.

This is not a new concept. In 1969, Dr. Elizabeth Kubler-Ross wrote:
“… [W]e found that all our patients maintained a little bit of it (hope) and were nourished by it in especially difficult times. They showed the greatest confidence in the doctors who allowed for such hope – realistic or not – and appreciated it when hope was offered in spite of bad news…”

We hear the word all of the time in caring for children with life limiting conditions and their families.
“I hope for a cure.”
“We hope for a miracle.”
“I hope that we can relieve his pain.”
“I hope that I can graduate.”
“We hope that she can go home today.”

What is hope and how can we support it? According to Chris Feudtner, MD, PhD, who has written widely about hope in the PPC setting, people feel hopeful if:
- They have a goal
- They have specific thoughts about how to accomplish this goal
- They have affirmative thoughts about their abilities to achieve their goal

Common themes of hope are (Keene-Reder & Serwint, 2009):
- Association with positive outcomes
- Future orientation
- Defense or coping mechanisms
- Relation to spirituality
- Innate to human nature

Hope and a realistic understanding of the prognosis are not mutually exclusive. Patients experience hope when they expect that a goal can be achieved. Consider this scenario:

Parents of a 5-day old baby with severe congenital anomalies can feel hopeful despite the fact that they have been told that less than 10% of such babies likely will live to 12 months of age. They hope that they can take their baby home, spend time with their family parenting their newborn, and have their baby see life outside the hospital. They feel confident that they can accomplish these goals after meeting with the hospital staff who supports them by reviewing pain/symptom management strategies and establishing involvement with a pediatric hospice team who will make home visits.

Disclosure is important. In the pediatric palliative care setting, children prefer to be told the truth, and half of those surveyed wished the information to be conveyed in a positive manner so that they and their families can maintain hope (Jamsell et al., 2016). This may seem contradictory. However, “…there is no
evidence that hope and realistic prognostic understanding are incompatible... there is evidence that they may coexist” (Rosenberg & Feudtner, 2016). Misunderstandings about the incompatibility of hope and realistic prognoses are partly based on the concept that there is only one hope (i.e., cure) when in fact there are multiple hopes. Concurrent hopes might include cure, minimal pain and symptoms, desired quality of life, time together as a family, discharge home from the hospital, and/or achieving milestones such as birthday, holidays, and graduation. Hopes will likely change over time. Provider disclosure of poor prognostic information has been shown to significantly promote parental hope. Disclosure promotes trust in their clinicians and parents were less likely to be distressed by the information. Hope is a powerful coping mechanism. Parents of children with advanced cancer, while accepting the reality of the child’s condition, remained hopeful (Kamihara et al., 2015). They were able to have “realistic hopes” including longer life, and the child’s well-being. They were also hopeful about others, including siblings and other children with cancer. Of these parents, three-fourths acknowledged that their hopes and their expectations differed, supporting the concept of “hoping for the best and planning for the worst.” During the palliative phase of a child’s illness, three-fourths of parents remained hopeful for meaningful time with their child, two-thirds hoped for a pain free death and one-third still hoped for a cure (van der Geest et al., 2015). Remaining hopeful for a cure was not associated with more long-term traumatic grief or depression.

In addition to values, prior experiences with health care and death, and family dynamics and coping, hope is very involved in decision-making. Interestingly, hopeful thinking was rarely associated with unrealistic expectations or inappropriate requests for treatments that were no longer beneficial. In the setting of pediatric palliative care, parental hopefulness is associated with more orders limiting life-prolonging treatments such as mechanical ventilation. Disclosure of accurate information allows both the child and family to prepare for the child’s death and make decisions consistent with their values. By not discussing and supporting hope, health care providers may undermine coping and decision-making and drive a wedge between themselves and the child/family.

Despite the importance of child and parental hopefulness, clinicians may still have difficulties with such conversations, focusing more on treatment-related topics (Kamihara et al., 2015). Health care providers fear giving “false” hopes, such as that cure is likely or possible. They may be concerned that no longer beneficial burdensome treatments may be pursued. The child may suffer more and may miss opportunities to make the remaining time more meaningful. Health care providers may fear that truth telling may be distressing to the child and family, and may take away hope that clinicians perceive is a comfort, a coping mechanism, and a support for “fighting.” Clinicians may not have the communication skills needed to inquire about the child or family’s hope and about other potential hopes. An uncertain prognosis, common in the PPC setting, can also be a barrier to such conversations. An uncertain outcome makes concurrent support of hopes and planning for alternative outcomes even more important. Parental statements of denial may be a coping mechanism and another barrier to conversation.

What are some of the strategies to support hope(s) yet “preparing for the worst” (Back et al., 2003; Smith, 2014)?

- Give equal time to hoping and preparing
- Align the child/family and clinician hopes
- Encourage and support a dual agenda of hoping and preparing
- Support the evolution of hoping and preparing over time
- Respect hopes and fears, and respond to emotions

Health care providers with higher levels of hope are able to support hopeful thinking in others, and are often skilled in these conversations and in pediatric palliative care in general (Thiel & Harris, 2005; Feudtner et al., 2007). Skills useful to foster appropriate hopes might include collaborating with the child patient and parents to establish meaningful goals, and enhancing emotions allowing achievement of goals. Why not routinely include hope(s) as a therapeutic support mechanism?
“After all, hope contains no mono or polyunsaturated fats, cholesterol, sugars, artificial sweeteners, flavors or colors; it’s classified as ‘generally recognized as safe’ by the FDA and is a known anticarcinogen.” (Munson, 1993, p. 733)

Words matter! Chris Feudtner (2005, 2009) has been very helpful in coaching us:

- Address hope(s) explicitly: "Given what we have just discussed, what are you hoping for?" “What else?” “How are these hopes faring?” Or: What are you most worried about? How can I/we best help?
- Enhance goal evaluation and selection: “Is it time to emphasize different goals?”
- Elicit thoughts about how goals might be accomplished: Present action scenarios such as pain management escalation strategies
- Enhance affirmative thoughts about abilities to achieve their goals: Help children and families create a narrative that makes sense of or derives meaning from the illness experience.

What does one say in response to an expression of a strong survival hope, such as for a miracle, when such an expectation is unrealistic? The clinician can certainly support hope in general and redirect the focus to smaller, achievable hopes such as improved pain control, and enhanced interaction with loved ones (Arzuaga, 2015).

In summary, hope is an important part of healing for children with life-limiting conditions and their families. Hope(s) change over time and significantly contribute to coping and decision-making. There are communication strategies to help clinicians elicit appropriate hopes, support the child and family, and enhance decision-making. I hope that this review has encouraged and supported your inclusion of hope as part of your management strategies in the pediatric palliative care setting.

Resources


When a child is identified and diagnosed and a family is now faced with the reality of their child’s illness, many forces come into play. One of them is the “Spiritual” factor. The first factor for consideration concerns the medical condition of the child. What, exactly, is happening physically? What options are realistic regarding treatment? As the basic physical issues of the child’s illness are identified, other factors come into play: financial resources, family emotional support to meet child care demands, ethical consultation, social work evaluation and recommendations. Attempting to get a complete picture, staff ask many questions and families attempt to answer, but are numbed by grief, fear, and an overwhelming sense of helplessness.

At this point someone from the Pastoral Care Department is invited to meet the family. The role of the spiritual care provider is to focus with the family on the meaning of what is going on. This relationship can provide families with a safe place to ask the “why” questions, to express outrage, deep sorrow, anger, confusion, and fear. In some circumstances families find their relationship to their own religious leader to be helpful, consulting with their Imam, Rabbi, Pastor, Priest, or other religious provider. Others will tell staff, “I am not religious, but I am spiritual.” Interfaith chaplains are trained to work with individuals from many different spiritual traditions and practices. Often those religious/spiritual boundaries become blurred as a family begins to feel supported by the chaplain. A unique aspect of spiritual care is that the chaplains will be present for extended periods of time, when families need to process.

It is imperative to note the spiritual dynamics at work among staff as they care for a child and relate to the family. Staff also attaches meaning to their vocation and the work they are doing. They may have strong feelings and values regarding how end-of-life decisions are reached, how to address a child who is in great pain. Frequently we hear families reviewing their experience with staff and noting how for this doctor or that nurse, it was more than a job. “They really cared!” is a common assessment by families regarding the palliative care medical team. Frequently families will single out someone from housekeeping, noting what a difference their presence made for their child and for themselves. Spiritual dynamics are present and impact each member of the medical team and of the family.

What is spirituality? Are there practices or patterns of behavior that might lead us to a working definition of spirituality? The concept of spirituality impacting health care is intriguing, but difficult to nail down. Someone complained that defining spirituality is like trying to nail custard to the wall.

Paul Pruyser, in a 1976 book, *The Minister as Diagnostician*, created a list of attributes that could be called spiritual. He suggested that these words are not technical or limiting to one faith tradition, but are universal words and concepts. They are:

1. **Awareness of the Holy.** What are the “ah!” moments, the “awesome” encounters? The opposite of awe is indifference, even contempt. Children thrive in settings where wonder and awe abound. So do staff. For a personal assessment of our spirituality we might ask ourselves, “Where do I stand on the awe to indifference continuum?”

2. **Does my life have a point or purpose?** How do I “fit” in this complex universe? Am I making a contribution? A mother whose child died after three days asks, “Did she make a difference? Was there a point to all this?” I replied, “I have no satisfactory answer, but one big thing I did notice was how her fragile short life brought your family together, people hugging, crying, caring
together. That is no small feat." That mother needed to know if there was even a small benefit from her daughter having been born.

3. Faith (understood subjectively). What can I count on, who can I trust, what challenges my faith? Children often talk about learning to trust the staff. Palliative care often works with a child and family for considerable lengths of time. Having faith in each other makes a great difference in the daily well-being of the child.

4. Grace or gracefulfulness. Grace is the capacity to look for the best, to be generous in word and deed, even to those who are struggling and ungraceful.

5. Reflection. The capacity to reflect on one’s experience, to be grounded enough to make changes rather than hold on doggedly to a self-defeating behavior. Making changes can be difficult as families face long-term care demands and parenting changes. Change can be difficult for the medical resident whose communication with children has proven to be sparse. A healthy spirituality means we can overcome our defense and alter our practices.

6. Community. A significant component of healthy spirituality is to be surrounded by a community. In Palliative Care such community begins with the child and family, and the medical team. Families that have a larger support team are indeed fortunate. Frequently the medical team is the community, as the child is supported by a single mom who may have another child at home. Often the compassion of the medical staff reaches out to the mother, filling in the gap as best they can.

7. Vocation. The spiritual dynamic of vocation is evident in many ways as a family enters into palliative care. Physicians, nurses, and other health care providers are exercising their vocation. How they perceive their vocation makes all the difference in how families perceive them. At the same time, the circumstances surrounding the family radically change as more time is needed for patient care. Parents are thrust into a job they did not wish for or want.

A common understanding of spirituality in relationship to children and their families is that we address children and family spirituality. We think of how they may be strengthened by sharing and active listening. Where an active faith or religious practice is one of their family values, we engage their religious community. However, especially in long-term relationships in palliative care, the spirituality of the staff becomes more and more visible. How we perceive our job or vocation, how we communicate awe and wonder gradually emerge for children and families to view. Thus the challenge in pediatric palliative care is not only to bring in a chaplain and address a child’s concerns, but to be aware that each one of us brings aspects of spirituality to our work.

Reference
A VILLAGE OF CARE

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It has been said that “it takes a village” to raise a child. My experience in pediatric palliative care (PPC) is that it also takes a village to care for a patient and family. According to Wikipedia (en.m.wikipedia.org accessed 5/12/17), in Great Britain, a hamlet would earn the designation of a village when a church was built. For the village that I am purposing, I suppose the hospital would be the central feature. Also, according to Wikipedia, a village is comprised of 5-30 families. It does not take long for the number of medical professionals involved with a palliative care patient and family to reach 30—individuals, yes, but representing the different families of professionals of the hospital. When you add the already established centers of support, such as family, friends, schools, faith groups, etc., you now have a nice community of care.

To live in the community of a village, one is in relationship with the various people and activities of community/village life. Spirituality is “an aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way that individuals experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred” (Puchalski, 2010, p. 25). In PPC, all the members of the village relate through connections and relate person-to-person, or, I would suggest, spirit-to-spirit as we each engage life through the spirit that animates our body. Thus, we live in relationship with ourselves and with others and with all that is important to us even if it is a special stuffed animal or blanket.

Because of its relational nature, spirituality encompasses the whole realm of PPC. Treatment decisions, care planning, direct services, and all roles of the palliative care team revolve around the meaning of life for a particular patient and family. By their own definition and prioritization, the family’s hopes and needs are the ingredients which will make life most meaningful during the remaining days, weeks, months, or years of the child’s life. Each member of the interdisciplinary team is an important resident of the village as we are facilitating and contributing to that meaning, relationally providing the skills of our training. We relate out of our professional roles because that expertise is needed. But in the delivery of care for children living with life-threatening illnesses and their families, we can offer our human self in order to form deeper and more meaningful connections. Being mindful of this opportunity, we will appreciate that each task that we perform has an inherent potential for spirit-to-spirit care that empowers the encounter with a depth of nurture that mere completion of the task does not provide.

The challenge of this relational delivery of care is that we can easily forget that the hospital community is not the primary source of care for the patient and family. While we enter into their journey in significant ways, we must maintain the appropriate boundaries so that we do not become the most important support people in the village. This is important both for the autonomy of the family but also for the self-preservation of the team. The team members offer their service by being fully present in the encounter, but then separate themselves because they are part of hundreds of similar villages with other patients and families.

Spiritual care is not so much the application of a particular discipline as it is an organic way of being in relationship with families. It is approaching a family’s life and how they experience and express meaning with reverence for their choices and ways of being on their particular journey. It is listening and affirming their approach, but also offering alternatives that may be beneficial.
In purposing this appreciation of the organic nature of spiritual care, I also want to acknowledge the importance of the “Spiritual, Religious, and Existential Aspects of Care” domain for palliative care. It is vital that we are assessing and responding to these aspects of care and using them to formulate part of the palliative care plan with ongoing assessment and documentation of concerns; that we are addressing and documenting spiritual/existential care needs, goals, and concerns and offering support consistent with the patient/family’s cultural and religious values; that we are providing rituals or practices as desired by the patient/family especially at the time of death; and that we are providing specialized palliative and hospice spiritual care professionals who will partner with the patient/family’s faith leader (Puchalski, 2010, pp. 17-19).

It becomes organic in that the essence of spiritual care happens when we are grounded in a relatedness in which we were all created, in which we are all born. It requires of us a mindfulness that will recognize and respect that children and families are living spiritual lives that connect with us in meaningful ways.

Four-year-old Ian needed to be told that his two-month-old sister would not survive an apparent SIDS episode. His parents asked that the chaplain and the child life specialist talk with Ian before his sister was extubated to allow a natural death.

“Your sister is very sick. She was not able to breathe and that made her heart stop beating. Even though the people who came with the ambulance were able to get her heart to start beating again, her brain became very, very sick. We are very sad because she is going to die,” explained the chaplain. After a pause of several seconds, the chaplain continued, “Do you know what it means to die?”

“It’s like when you blow out a candle, the light goes out,” Ian responded. “What happens to the light when it goes out?” the chaplain asked. “The light goes to God,” Ian proclaimed with no hesitation.

Ian was prepared to go and see his sister with parents overwhelmed by grief and by amazement that their young son could speak so powerfully to what was happening. The parents later reported that though they were active in their Catholic faith and rituals, they had never had such a conversation with Ian. His thoughts and imagery were completely from his own spiritual understanding.

Several weeks later, the chaplain made a bereavement call to the family. Ian’s father spoke with awe as he shared the story of Ian entering his parents’ bedroom and finding his father crying. Ian reached for the tissues, and crawled into his dad’s lap and gave him a hug. Ian explained: “Every day you get a box—kind of like a present. Some days you get good things in the box and some days you get bad things. The good part is that you know you will get a new box the next day.”

Volumes have been written by theologians, philosophers, scientists, and others to explain the mystery of life and death and the reasons that bad things happen. There are times when we only need to trust the simple spirituality of our children to help us understand the complexities of life.

Spiritual care in PPC is living in the village and allowing space for such amazing insights to happen. It is not about what we might do, but rather how we might be present to create a safe space for reverence and silence and pondering words that cultivate the sacred moments that we share with these amazing patients and families.

References


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2016 was a year of revelation for me. A year I would have never predicted. We all have our “stuff,” our crosses that we carry, and in my view the tools that I thought God intended to use for opportunities for spiritual growth. God did, and still does use my crosses as a path to teach me, but in 2016 he took me on a completely foreign path that has profoundly changed my life.

I believe it started with pondering what my role was in Supportive Care. As an OT, I have always focused on treating the whole person. This means addressing any skills anyone may need to perform in life roles such as a family member, community member, student, or friend. Sometimes that means teaching people how to do tasks like getting dressed while being physically challenged or it could mean teaching coping skills to deal with life stressors. Essentially, I help my clients learn to perform the skills necessary to live their lives with meaning.

I started to consider if supportive care could really mean more. What exactly did it look like? The next week at Church, Pastor Rose seemed to address just this. He spoke of loving your neighbor as God has loved us and loving your neighbor as yourself. Now, this really perplexed me, because I consider myself a kind, loving person, but how do I really love someone like God loves me? Pastor spoke of having a nature of submissiveness, in which having your way is not a priority; showing mercy to others; providing practical help by serving others in need when God puts you in a situation in which a person can’t do for themselves; bearing good fruit through acts of goodness; sincerely being honest about our struggles; allowing people to see the light within you; projecting an attitude of being approachable and willing to listen; and giving grace to others in the same way I have received it. I realized that loving your neighbor is supportive care.  Cognitively I was beginning to understand, but I was far from living this.

Then “D” came into my life. I received orders to work with a teenage female who had a self-inflicted injury. This was not uncommon; I had extensive experience working in Pediatrics. I walked into the room to find a girl with a significantly injured face, who could not talk, had uncertain vision and cognitive processing. I performed my routine evaluation talking to “D” as I went. I always function under the assumption that people do understand me, for how terrible it would be to understand but not communicate and have others treat you as if you were not there. At the end of the session, I asked her if there was anything she needed. She raised his hands and gestured toward herself with both hands. Not understanding, I asked her to write on a dry erase board. She wrote “hug,” and the door for God’s love to walk through opened.

So I walked the path with “D” through weeks and months of treatment in which she initially could not talk, walk, or dress herself. She had vision in one eye and hearing in one ear. She had over 20 surgeries that often left her in severe pain. I watched in wonder as “D” would persevere, pushing on again and again, coping, surviving, and achieving, even though she came from a place of inability to cope. I watched her connect with everyone who came into contact with her, when her nature was a preference to be alone, not express herself, and dislike touch. She endured a series of painful surgeries as well as emotional repercussions from her injury that affected not only herself, but also her family and friends. God was clearly working through “D” and revealing Himself to me through my work with her.

As our time together progressed and “D” was able to write more detailed messages, we began to talk about our faith. “D” and her mother were Christians so I felt at ease discussing our shared belief. We discussed the way that God takes difficult events and uses them for His good. How there was purpose and a path for “D.” I explained to “D” that I saw life like a piece of plaid ribbon. All the people in our lives are threads in our ribbon and I was sure that she was a gold thread in my life ribbon because of how much I have learned from her. I told her I knew God was revealing Himself to me through the works that
He was performing in “D.” I was thankful and amazed how “D” was progressing. God was not only revealing Himself to me, He began to use me as a door for his love to walk through.

At first, I simply was doing my job as I always do. Helping “D” set goals and develop a plan to achieve them. There were so many “what ifs” in her recovery that our goals would change frequently according to her medical status following each procedure. “D” had become accustomed to writing on her dry erase board in response to my questions. At first she hated this, but eventually accepted it as a way to communicate. We were unsure if she would ever speak again, as she had a tracheostomy in place for an airway. Eventually, “D” was able to dress herself, perform her grooming, and walk with an assistive device.

One day I was off work and out with my son and his friend at a restaurant. I received a voicemail from a dear friend and “D’s” Speech Therapist, (a message that is still on my phone) saying “Karen, someone has something to say to you.” Then I heard “D” say, “Hi Karen, this is “D.” I sat in the doorway of the restaurant and cried, tears of amazement and thankfulness, God’s glory revealed. I later told “D” that that was one of the best days in my life; I think it always will be. “D” continued to progress moving from acute care, to rehab, and back to acute. She was making such gains that we began to work on higher level skills such as coping skills, communicating your feelings assertively, and self-management.

As “D” was preparing to discharge home, a number of circumstances occurred that left her without family or friends close by. I would say to her on Friday, “OK “D” it’s Friday; that means I won’t see you until Monday.” Then she would say, “Can you come in this weekend and see me?” “Yes, I would be happy to,” I’d say. The truth was I really was happy to. Just as our Pastor spoke of submissiveness, having my way didn’t feel so important, because “D” was asking and I wanted to be there. This was not time I spent as an OT, it was time spent allowing God’s love to flow through me. I felt God had put me in this situation because her family could not be there and I could.

Sometimes we walked and talked or played games or crafts. Other times I let God’s love work through me through practical help by doing her laundry, buying clothing items she needed, or setting up an appointment to get her a haircut. At the time “D” was preparing to go home she went through a series of significant stressors, including multiple disrupted discharge plans, a life-alternating illness of her mother, separation from her sister, and more surgery. As I walked with “D” through each experience, experiences that brought me to tears, God showed us again and again that He is faithful; He is in control and will bring good out of devastating situations. Twenty-five years of working with adolescents told me that “D” would respond with anger, sadness, and frustration. Instead, with God’s divine love, “D” responded to each setback with calm faith.

As I was yielding to God’s will, so was my family. Now, because of confidentiality I can’t talk to my family about my patients. My family knew that I had a patient that made my heart elated or heavy depending on the circumstances of the day. They knew that I went to see her on Sundays, and they listened to me complain for four weeks about the delay of the arrival of a Skillet T-shirt that I had promised her. One day my son called me into his room. He was ordering a cross necklace from Amazon and was going to get me a matching cross, then he said “that kid at work seems pretty important to you, I think she should have one, then she will always be connected to our family even when she leaves.” “Yes, she will,” I said. “D” loved the cross.

I will not pretend that “D” leaving was easy. Reason said that this is what we were working for, but my heart ached to hold on. It still aches, but I can smile and remember the blessings of the journey God had taken us on. God was always ahead of us leading the way, reaching out His hand to us. He was calling me to be the door for His love to walk though, in whatever circumstance that was presented to me. He was calling “D” to recognize that He has a plan for her life, and had given her the skills to survive and flourish. “D” is discharged, home with her family out of state. She was supposed to come back for further surgeries but has not done so. Understandably, I presume her family opted to have surgery closer to home. I am reminded that God’s ways are not our ways, that when we pray for His will to be done, that it may not line up with what we think the agenda should be. I continue to learn, grow, and trust in God’s plan.
Today as I write this, I look up on my dresser at home. On it sits a picture “D” gave me of us standing side by side. Beside it is a framed picture that “D” drew of a cross that says “when you walk through the waters I will be with you.” These are my prized possessions. The biggest prize however is the revelation of what it means to love your neighbor as yourself and as God loves us. This means being the door for God to walk through. The door that we are all called to be.

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“I could never do what you do.” I hear that statement over and over nearly every day. First of all, people say that about being a hospital chaplain and dealing with death and illness on a daily basis. Secondly, people echo that statement when they learn that I am a pediatric chaplain and I help care for sick children and their families. Even my fellow chaplains and clergy colleagues claim that they could not do what I do. For me, serving as the pediatric chaplain at The University of Kansas Health System is a great blessing in my life. Let me share some of the reasons why.

My ministerial journey began with Children’s Ministry with the opportunity to provide spiritual support and education to children and teens of all ages. I have connected with children in some way throughout my whole life, whether it was through sports, education, or spirituality. So it was a natural segue, for me, to work with children in a hospital. In my role, I provide spiritual and emotional support to children and families in the Pediatric Unit and the Pediatric Intensive Care Unit (PICU), with parents in the Neonatal Intensive Care Unit (NICU), and with women who are hospitalized before their baby’s birth, called antepartum moms.

As chaplains, we attempt to provide a non-anxious presence to patients and families who may be in crisis, receiving difficult news, or even undergoing routine medical treatment. Our role is not to force our religious beliefs on people, but to offer active listening and meet people where they are in life’s journey. For some, this may mean arranging for sacramental needs to be met such as Anointing of the Sick, hearing confession, or providing a baptism. For another, this may mean listening to a distraught mom who doesn’t know how she is going to keep her job while one child is sick and two others are at home. For others, it may mean reaching out to the religious leaders from the Hindu, Buddhist, or Jewish traditions. So, who ya gonna call?

In sharing a few concrete examples, I can best display the diverse roles a pediatric chaplain might experience. Many times I work with antepartum mothers who may be in the hospital for months at a time as they allow time for the baby to develop. We have many high-risk pregnant patients at the hospital, so many mothers are hospitalized while the medical staff provides on-going medical support for mom and the baby, and the babies are monitored. One of my favorite and more memorable experiences was with a mother, Mary, who was on bedrest for several months. Mary was a hospital employee that I had known previously from our work together. She had shared with me her desire to get pregnant and her fear since she had previously experienced two miscarriages.

While Mary was hospitalized, I made periodic visits to her room often listening to her concerns and fears and providing prayer and encouragement. It’s never easy for these mothers to be away from home and sometimes there are other children who tend to pull them in two different directions – caring for the baby in the womb and caring for the children at home. Finally, Mary’s baby was born and although small and premature she was fairly strong. After the additional months in the NICU and many more conversations with these parents, I was asked to provide a baptism for this “miracle” baby in their home. This family was not going to be able to go to church for many months due to the precarious condition of their baby’s lungs.

At the baptism, family and friends were gathered at the baby’s bedside and I had the privilege to baptize and welcome this little one into God’s family. This situation demonstrates the continuum of care that a dedicated pediatric chaplain can provide to a family. I continue to see this child periodically when she
comes for her check-ups at the Neonatal Medical Home and whenever I see the father he introduces me to others as “the pastor who baptized their baby.”

Not all situations end in such a positive way. Many times I am contacted after the birth of a baby with known anomalies who may live for just a short time or for a baby that dies at birth. These times are difficult and families often need the reassurance that their baby is loved and that he/she is safe. Questions of faith and anger at God may be typical responses at the death of a newborn baby. Chaplains can provide spiritual support in these heart-breaking times and may offer reassurance as well as empathy with the angst and despair of this major loss. Many families want to have their baby baptized or blessed at their death. Chaplains often set aside their theological beliefs and provide support consistent with the family’s preferences.

Along with the strong support of the labor and delivery nurses, brief memories of this child will be reinforced through handprints, photographs, baptismal shells, and receiving blankets. In the past, babies were whisked away before the family even had the chance to hold and cuddle the child. Studies have found that parents do better with an opportunity to grieve for the child rather than ignore his/her existence. Dr. Deborah L. Davis in her excellent book Empty Cradle, Broken Heart states that:

The death of a baby is a profound loss, and parents need to grieve this loss. To hold their baby before, during or after death is now seen as an opportunity to love and gather memories of the baby. Feeling sad, angry, helpless, or lonely is now viewed as a healthy reaction associated with grief. Talking about the baby to someone who can listen is now considered therapeutic. (p. 7-8)

Medical staff and pediatric chaplains can learn to provide a peaceful transition and recognition of loss in this brief life. In doing so, the suffering of the parents will be acknowledged and memories made to assist them in their grief process.

As for any chaplain, a pediatric chaplain must come to the understanding that there will be suffering in the world. Theologians call this the theodicy of suffering where we try to understand the teeter-totter balance between believing God to be all-loving, all-knowing, and all-powerful and the fact that children get sick, die from cancer, or suffer traumatic injuries. As parents struggle with these issues, there is no better person to engage in theological reflection than the pediatric chaplain. So, who ya gonna call? Call the chaplain. We can spend time exploring the theological and existential questions that parents or teenagers have.

The next patient experience I want to explore with you is David. David was a young teen who was intelligent and exploring his own faith identity. He had accepted the faith of his parents – Jehovah’s Witnesses – and spent time with the elders of his faith exploring what it meant to live out the beliefs of his faith. Jehovah’s Witnesses believe the Old and New Testament “command us to abstain from blood” and that “God views blood as representing life” (https://www.jw.org/en/jehovahs-witnesses/faq/jehovahs-witnesses-why-no-blood-transfusions/). David had cancer and I spent time with David and especially David’s father learning how we could best provide spiritual support to David and his family. After talking to his father, I prepared a summary of our conversation for the staff reinforcing that minimal blood would be taken for tests and that the patient (and his father) did not want to have a blood transfusion.

David was progressing in his cancer treatment until the time came when he became gravely ill. Medical staff felt that he needed a blood transfusion to save his life and family felt this was against their beliefs. An ethical, spiritual, and medical dilemma progressed to the point where medical staff, feeling a legal and ethical responsibility to provide blood to a minor patient, received a court order to provide blood. The parents brought in the elders of their church to support them and David during this time.

As David’s chaplain, I spoke with all parties involved and attempted to be an advocate for the spiritual beliefs of David and his family. Mom and dad were adamant that David not receive a transfusion and the church elders shared conversations that they had with David regarding his desire to refrain from transfusions. Several intense days passed and eventually David’s condition deteriorated even more and
he was given a transfusion against his family’s wishes. Despite the transfusion, David died. My role in this situation brought particular angst for me as I personally believe in using all medical interventions available, yet I am called to advocate for a patient’s spiritual beliefs. To this day, I wonder if David’s family still believes that it was the blood transfusion that resulted in his death.

Many of our long-term pediatric patients come to see the hospital as a second home. Some spend more time at The University of Kansas Health System than in their own home. These children will often become connected with the Palliative Care team. Part of the goal will become to help the child understand the progression of their illness and that possible death may arise from their condition. The pediatric chaplain may assist in helping the child and their parents assess their desires at death. Depending on the age and developmental level of the child, the chaplain may support the child to ensure that he or she has more choice and autonomy in his or her own medical treatment.

One such young adult was Sharon who spent many years receiving treatment for her illness. We spoke many times and Sharon was able to achieve many of her school goals including attending her graduation and the Prom. When her death became imminent, she began to speak more about her faith and her desires at the time of death. We talked about how she was feeling and how she was worried about her family. We talked about her belief in God and the afterlife she would experience. Although I had been providing care for Sharon for many years, she reached back into her early faith development and asked that a priest come to perform the Anointing of the Sick ritual and offer support. I could have taken offense, but my goal is to support each patient with their spiritual needs. I’ve learned over the years that many former Catholics will return to the faith of their youth at the time of death. One of the benefits in the Catholic faith is the familiarity of the sacramental and ritual traditions when a person nears death. Sharon wanted to know that a priest had prayed with and anointed her.

More recently, a child was going to be taken off life support and the family was Christian, yet from another country where they have a tradition of laying a colorful cloth over the deceased. When we had the family meeting to develop a plan, I asked whether there were any traditions from their home country and this was discovered. I was able to share this information with staff so that the cloth could be placed over the baby after death. The family expressed comfort that their tradition was honored at the time of their child’s death.

I find one of the most effective questions to ask at this time is “How can we best honor your family and spiritual traditions at this time?” Various faith traditions have unique rituals at death and the pediatric chaplain can be one of the best resources. I could go on and on about the unique situations and the amazing opportunities I have had to be “God’s representative” to patients and families. I am truly blessed to serve as a pediatric chaplain. So, who you gonna call? How about calling the chaplain…it is our job to assess, discern, and provide spiritual support to people of all faiths and even people with no faith tradition.

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When a child is diagnosed with a life-threatening or life-limiting illness, it can be difficult for the patient and family to find solace in their faith. Laments like: “Why is this happening?”; “God, what did I do wrong?”; “Why aren’t you answering my prayers?”; “Knock, knock. God, are you there or on vacation?” Crying out laments where one feels orphaned and abandoned by the holy.

As a pediatric palliative care chaplain one of my roles is to offer space to explore, where is God in all this (WIGIAT)? As patients and families try to make sense of illness and death, I quickly found that having only a conversation with patients and families did not elicit deeper conversations. Using art as a means for spiritual and religious reflection is helping to engage the patient and family to explore WIGIAT.

For the past four months I have used three different forms of art. First is the God’s Eye activity. The patient/family wraps yarn around sticks to make a simple God’s eye based on the traditional Ojo de Dios from the Huichol Indians of Mexico’s Sierra Madre. The Huichol Indians bring this as a symbolic gift to deities in sacred caves in the hope of the return of favor and protection. When I give out this activity I provide the meaning of each color in a color chart.

I used this God’s Eye activity with Abby who is a 19-year-old girl who has lived with leukemia since she was 9. I have been making bi-monthly visits in the outpatient clinic and visit when she has comes to the emergency center or during admissions. Abby’s mom always accompanies her, which can make it difficult to have spiritual conversations. To break up the long waits to see the doctor in the clinic, I brought the God’s Eye activity and after it was completed, she shared the following about the above picture:

- Red in the center is the blood of Christ. Jesus paid for our sins and heals everything inside my body and out. Soon he will get rid of all the diseases one day.
- Blue/green represents health. Green is the book of Genesis and the second day of creation, the parting of the sea and land.
- Gray means strong. God is my rock. Build a house on rock not sand.
- Yellow means light.
- White represents God who is almighty and pure.
- After she described each color, Abby reflected quietly and wanted me to hang the God’s Eye on her IV pole.

Abby expressed that God is her center and healer. She is fighting hard to become free of leukemia. Genesis represents a new beginning on the earth of sea, land, and rock; a solid, strong foundation.
Christ died and became light and pure for me.

Abby has recently confronted her mortality and is making meaning of her eventual death. She told me God will be welcoming her with open arms.

I also used the God’s Eye activity with Boyd, a four-month-old boy who suffers from hypotonia, seizures, and a life-limiting genetic condition, and his Grandmother. I visited weekly with Boyd’s Grandmother, his primary caregiver, during her emotional roller coaster ride until his recent death. God’s Eye helped in building trust and relationship building.

She shared the following about her God’s Eye:

- The inner gold reflects a very bright pupil where God sees everything. There is a light through God’s pupil.
- Silver is God’s thinking, caring, and happiness for us.
- Dark purple represents her Lord and the crucifixion.
- Yellow He lives! Resurrection
- Lavender means God’s peace. The peace we only have through him.
- The gold string points back to God’s eye.

Grandmother said that despite Boyd’s condition, God is always present in death and new life with God.

When Boyd was moved from a regular room to the pediatric ICU, his Grandmother was sharing her hope that Boyd would go home and his illness will be treated to “buy more time.” Unfortunately, Boyd kept declining despite different therapies.

In working with Boyd’s Grandmother, I offered her another tool to help make meaning of the emotional roller coaster. This is the second example I want to share here. I chose a form of poetry, a cinquain. It is a French word for five. The idea is to have the patient or family choose a word they want to have deeper insight. Line 1 is a one word noun. Line 2 adds two adjectives. Line 3 adds three verbs. Line 4 adds a four word phrase that sums up or further describes line 1. Line 5 is one word that refers back to the title of the poem.

Throughout Boyd’s ICU stay up until his death, Grandmother shared with me a sequence of her emotional roller coaster.

1. Ocean
   power, boundaries
   relaxing, amazing, calming
   powerful but with boundaries
   sound of calming strength
   beautiful

2. Wind
   strong, unseen
blowing, damaging, calming
here but not seen
can bring much fear
relaxing, peaceful

3. Ventilator
life, machine, horrible
Supporting, sustaining, existing
only life for some
scary

4. Brain
cells unknown
researching, computing, connecting
by far greatest computer
mystery

5. Breath
living, breathing, flowing
fragile, precious
God gives to us
we take for granted
life

6. Waterfalls
beautiful, rocks, erosion
splashing, rushing, deceiving
makes its own path
deceiving

7. Lake
still, boating, thinking, swimming,
water
reflections, many storms over water
serenity

Grandmother told me the day before Boyd died: “He’s (God) got it. I need to leave it alone.” Using this simple poetry, Grandmother was able to make meaning of her journey with Boyd.

Spiritual support is not limited to relationships with other people but to varying extents relationships with God or a Higher Power. Using art is a form for a patient/family to search for meaning in the midst of serious illness. Boyd’s Grandmother’s poetry told the story when Boyd first entered the hospital. She felt at peace and hopeful when she thought Boyd was improving. After weeks of deterioration and being placed on the ventilator, Boyd continued to have many seizures. At this point, Grandmother became angry and began to express her grief. The end poems describe Grandmother’s realization that Boyd was going to die and she did not like that because she wanted more time. Her last statement to me was her realization that she was unable to control any of this. Boyd died three days later.

The willingness of the patient and family to allow me to share how they feel about WIGIAT teaches me there are all sorts of different venues to help pediatric patients make meaning of their illness and its trajectory. This experience teaches me that art connects us to our heart, to each other, and to the power of the Holy.
A third example of using art to facilitate spiritual exploration is seen in one of my first visits as the palliative care chaplain with Ryan and his mom. Ryan is 15 years old whose diagnosis is: cerebral palsy due to anoxic brain injury at birth, developmental delay, and seizure disorder. Ryan’s mom shared with me that she “believes in God and is getting her strength from God. I rely on God to lean on when the times are hard.”

I offered mom the coloring book for the soul, *Sacred Symbols Coloring Experiences for the Mystical and Magical* by Lydia Hess. Hess writes, “The ageless icons and emblems of spiritual experience embody our innermost, longings, our dreams and vision, and our connection to that which is greater than ourselves.”

Mom chose many pages to color. The first one, Creation, is about the bond between mom and Ryan. She pointed out the little face on the right as hers beside Ryan. Cycles, harmony, union, shield, ascend, dimensions, cosmos, strength, protection, awakening, endurance, interconnection, unity, love rise, and life are all descriptors of God. The final page, titled, “The End,” reflects Ryan’s eventual death.

During our time together, mom was able to name her relationship with Ryan, God, and began to think about Ryan’s death. Mom became tearful and identified the reality that Ryan will die.

These examples are ways in which I have been able to use art as a means to facilitate spiritual exploration.

1. Oklahoma Historical Society, God’s Eye.
2. Cinquan, Poets.org

Summary: Art contributes to a patient/family’s imagination to explore and dive deeply into sacred traditions. As a palliative care chaplain I can support them in discovering new, personal, even healing encounters with God a Higher Power as they see it.

Reference:

This article provides an overview of current research related to religion and spirituality for pediatric patients and families, describes the available spiritual assessment tools and care process for pediatric patients and families, and suggests areas of future research that could help inform and strengthen healthcare teams’ provision of spiritual care to children and families.

Introduction

Healthcare providers readily acknowledge that spiritual care is an important part of caring for patients, particularly those facing life-limiting health challenges (Balboni et al., 2013). Additionally, in 2001, JACHO made spiritual assessment of patients a national requirement, but did not establish clear requirements in terms of what constitutes a spiritual assessment or how to use information gathered (Hodge, 2006). Even with widespread acknowledgment of the value of spiritual care for patients, confusion exists on multiple levels as to how to provide spiritual care in the healthcare context, particularly for pediatric patients, where both children’s and parents’ spiritual care needs are part of providing family-centered care.

Understanding the meaning of “spiritual care” for pediatric patients and their families necessitates a clearer understanding of the terms “religion” and “spirituality.” Although “religion” and “spirituality” are often used synonymously, these terms have somewhat different meanings. Religion is traditionally described in relation to institutional factors, such as membership in a specified faith community, religious service attendance, denominational affiliation, or religious preference (Gallup & Lindsay, 1999). Usually, religion includes a social dimension and a focus on canonical texts or other forms of shared knowledge, including shared faith, practices, rituals, or beliefs that help a person express his or her connection to a higher power (Davies, Brenner, Orloff, Sumner, & Worden, 2002). Alternatively, spirituality is frequently understood as one’s personal search for meaning or connection to something greater than oneself considered to be meaningful, such as a Higher Power, Sacred Source, divinity, or God (Robinson, Thiel, Backus, & Meyer, 2006; Taylor, 2015). Spirituality can involve meaning making through intrapersonal, interpersonal, and transpersonal connection and can be a guiding force, inner source of power, or source of wisdom (Taylor, 2015). Spiritual care can encompass provision of care in any of these religious or spiritual dimensions.

While some research explores the link between religion/spirituality and child well-being, less is known about the role of religion and spirituality for pediatric patients in the context of illness, disease, or other major health events. More of the published literature reveals how religion and spirituality play a role for parents of ill children. What follows is a discussion of which pediatric patients and families tend to draw upon religion or spirituality, how religion or spirituality play a role for ill children and their families, how spiritual assessment and care for pediatric patients and families can be approached, and future areas of research necessary to strengthen spiritual care for ill children and families.
Pediatric patients and families for whom religion or spirituality is influential

Although religion and spirituality may be important for any child or family coping with sickness, or facing suffering related to physical or mental health-related events, research suggests that religion and spirituality are particularly influential for parents coping with a child’s serious or terminal illness (Barnes, Plotnikoff, Fox, & Pendleton, 2000; Fitchett et al., 2011). Parents of children receiving pediatric palliative care report using spirituality or religion to find meaning in the experience of caring for their critically-ill child. Those parents who turn to religion or spirituality often do so to find comfort, and report acceptance of their child’s illness outcome, even if that outcome is death or disability. While feeling sorrowful about such an outcome, these parents rely on religious or spiritual beliefs to ease their emotional distress (Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011). Ultimately, belief in God or a higher power has been shown to help parents feel their child’s life, despite its length, had purpose and meaning (Haut, 2015).

Occasionally, parents appeal to their religious or spiritual beliefs in expressing hope for a miraculous recovery for their child, even in the midst of a poor prognosis by the health care team (Arzuaga, 2015). It is important to note that in cases where miracles are invoked, the reason behind such a belief can include the sincere conviction that supernatural healing can occur, misunderstanding about the patient’s diagnosis or prognosis, unpreparedness for a child’s death, rejection of proposed treatment or demand for treatment that the health care team deems inappropriate, or mistrust of the health care team (Delisser, 2009; Sulmasy, 2006; Wagner & Higdon, 1996). In many cases where a family expresses hope for a miraculous recovery, conflict between the family and the health care team results (Rushton & Russell, 1996).

Although less is known about the importance of religion or spirituality for ill pediatric patients compared to their parents, available research does suggest that spiritual care could be an important adjunct treatment for children (Houskamp, Fisher, & Stuber, 2004). In particular, several studies explore the role of spirituality in children or adolescents with cancer. In these studies, children and adolescents primarily used spirituality as a therapeutic resource or coping strategy, or viewed spirituality as a source of meaning during their illness (Espinha & de Lima, 2011). Research also reveals which pediatric patients are likely to initiate spiritual care. For example, adolescents facing “mental health issues are significantly more likely to request spiritual care on their own, than any other group of hospitalized children” (Chapman & Grossoehme, 2002; Grossoehme, 2008).

The role of religion and spirituality for ill children and families

For some pediatric patients and families, religion and spirituality influence the types of decisions they make when illness presents. In one study, pediatric patients who identified as Christian or Catholic had a DNR/POLST order more often than patients who identified as another religion (Buddhist, Hindu, Mormon, Muslim, Jewish, and Jehovah’s Witness), 63% vs. 36% (p< 0.01) comparatively (Brock, Steineck, & Twist, 2016). In other studies, parents felt their religious beliefs guided them in their moral responsibility and behaviors as parents to their ill child, but that at times there were no decisions to make (Boss, Hutton, Sulpar, West, & Donohue, 2008; Hexem et al., 2011).

In addition, rituals requested or performed during a child’s illness or at the end of a child’s life often derive from religious or spiritual beliefs. Families may request that a child be baptized, that prayers be said on the child’s behalf, the sick child be anointed, or religious or spiritual symbols of meaning be placed near the child’s bedside. Families may perform culturally specific rituals that encompass some of their religious or spiritual beliefs. For example, Latino parents with indigenous beliefs may request the use of herbs or natural remedies to perform healing rituals in an effort to remove evil spirits from the sick body. Families with Asian heritage may give special foods in an attempt to restore energy balance (Mazanec & Tyler, 2003). Other families may request the use of alternative medicines, which are linked to their religious or spiritual beliefs, in treating their child (Campbell, 2006). Additionally, some ethnic minority families, will choose to seek medical help from traditional healers before accessing care through formalized medical establishments (Cardenas, Garces, & Johnson, 2007). It is important to note that rituals are not always religious or spiritual in nature; they sometimes meaningfully acknowledge a person, event, or circumstance (Baird, 2015).
Although religion and spirituality are usually a positive lens through which to view a child’s illness, some studies indicate that parents of ill children feel spiritual distress or even disconnect from their religion or spirituality during times of their child’s illness or death. If a child’s prognosis is poor or illness results in a significant health event or death, parents may feel let down by God (Bingen, Kupst, & Himelstein, 2011), become angry with or question God (Armentrout, 2009; Bingen et al., 2011; Hexem et al., 2011) or feel that the child’s illness is a punishment from God (Hexem et al., 2011). For example, Latino individuals have been reported as interpreting pain and suffering as a form of punishment from a spiritual power and a test of personal fortitude (Davidhizar & Giger, 2004; Munet-Vilaro, 2004). Other families do not necessarily experience negative religious coping when their child is ill, but view their child’s illness through the lens of their religious or spiritual beliefs in such a way that suffering is prolonged. For example, individuals from India, Bangladesh, Nepal, Pakistan, and other South Asian countries believe in reincarnation pain, so may be more willing to accept pain for their child when it occurs (Wiener, McConnell, Latella, & Ludi, 2013). In instances such as these, health care teams may struggle with how to reconcile their duty to relieve the pain and suffering of the child with the goal of supporting the family’s spiritual beliefs. Resources such as institutional bioethics committees can be helpful when conflicts arising over such issues become intractable.

**Spiritual assessment of pediatric patients and families**

Under the broad category of “spiritual assessment,” distinctions are made between a “spiritual screen,” “spiritual history,” and “spiritual assessment.” A spiritual screen is a brief means for identifying the patient’s faith affiliation and/or cultural needs related to religion/spirituality (i.e., dietary restrictions), whereas a spiritual history is more lengthy and explores how the patient’s or family’s religion/spirituality affects health care. Alternatively, spiritual assessment may be defined as an in-depth exploration of the patient or family’s religious or spiritual make-up with the goal of developing a treatment plan. Spiritual assessment has largely been the role of chaplains or spiritual care personnel, who are viewed as spiritual care specialists; however, increasingly, other health care professionals, including physicians and nurses, are considered to be spiritual care generalists, and thus appropriate members of the health care team to perform spiritual screens and histories (LaRocca-Pitts, 2012; Taylor, 2015).

Use of tools to assess a child and/or family’s religion and spirituality can be helpful in that such tools help clinicians or chaplains examine the child and family’s religious and spiritual resources and needs to better provide care. Spiritual resources include values, beliefs, and practices that children or families possess, that may help them understand an illness or health state. Spiritual needs are elements of brokenness, beliefs, or practices that children or families lack, which prevent them from feeling whole (Grossoehme, 2008).

Until recently, questionnaires used to assess religiosity or spirituality in the pediatric context have been adapted from adult protocols (Hill & Hood, 1999) and most assessment tools that exist were developed from a western Judeo-Christian perspective (Taylor, 2015). However, one pediatric-specific tool, the BELIEF pneumonic (Belief system, Ethics, Lifestyle, Involvement in a spiritual community, Education, and Future events), was proposed by (McEvoy, 2000) in 2000 and is a tool for pediatric clinicians assessing a child or family’s religion and spirituality. Additionally, (Barnes et al., 2000) and colleagues have suggested several questions for assessing a family’s religion and spirituality and how it might impact the illness experience. Examples of questions they propose include: a) “How does the family understand life’s purpose and meaning? b) How do they explain illness and suffering? c) How is the specific illness of the child explained?” (Taylor, 2015). In 2008, Grossoehme conducted the first known research study to develop a spiritual assessment tool specific to hospitalized children and adolescents. The Child/Adolescent Spiritual Screening Tool (CASST) contains 17 questions designed for use by a chaplain in assessing child/adolescent spirituality. Other available spiritual assessment tools, developed for adults, include the CSI-MEMP, FICA, HOPE, FAITH, and SPIRIT. While such tools are sometimes adapted to the pediatric setting, these may not adequately capture the specific religious and spiritual needs of children and families (LaRocca-Pitts, 2012).
Selection of a spiritual assessment tool will be dependent on the spiritual assessor’s credentials (i.e., chaplain vs. clinician), since tools, such as the CASST, are designed specifically for chaplains, whereas others, such as the BELIEF pneumonic, are more tailored to clinicians. Triggers for spiritual assessment might include a significant change in the child’s disease course or condition, receipt of a new diagnosis or bad news from the clinical team, or distress related to the child or family’s life, which may or may not be disease-specific. Spiritual screens, histories, and assessments, while important to perform, are not to be confused with attempts to integrate the spiritual assessor’s own religious or spiritual views; rather, understanding the importance of the role of religion or spirituality for a child and family helps the spiritual assessor incorporate such values into the child’s plan of care (McEvoy, 2000).

Those who directly assess children’s religious and spiritual needs should keep in mind that children are less likely than adults to be offended by questions of a religious or spiritual nature. Creating a non-judgmental, safe environment for children to talk about their understanding of religion and spirituality may elicit profound insights that help guide care for the child and his or her family (Taylor, 2015). For example, one question that is particularly helpful with 6- to 18-year-olds is: “If you could get God to answer one question, what one question would you ask God?”(Taylor, 2015, p. 658). A key element when assessing a child’s religion and spirituality is to always allow the assessment to be guided by the child’s cognitive and faith development stage (Taylor, 2015). Seeking permission from parents before performing spiritual assessment of their child is usually ideal, particularly in the case of younger children. Yet performing spiritual assessment of children in the presence of their parents is context specific and the individual performing the spiritual assessment should consider the child’s preferences.

Spiritual care for pediatric patients and families

Although religion and spirituality are important to many children and parents facing illness, studies indicate that the amount of spiritual care children and parents receive, particular in the acute care setting, is insufficient (Fitchett et al., 2011). Increasingly, spiritual care is understood to be part of every health care provider’s role. And reportedly, direct care providers frequently receive requests from families related to spiritual needs. For example, several studies show that pediatric oncologists frequently receive requests to engage in prayer with parents of ill children. When this occurred, providers responded variably, sometimes engaging in prayer with the parent, other times accommodating prayers but not participating, and still other times directing families to spiritual care providers, like chaplains (Cadge & Ecklund, 2009).

While clinicians may be in a pivotal position to perform a certain level of spiritual assessment, (i.e., spiritual screens and histories) they may feel ill-equipped to provide in-depth religious or spiritual assessments or provide specialized spiritual care to children and families. Clinicians who detect deeper spiritual needs, or are asked to provide spiritual care that they feel unprepared to deliver, can refer children and families to spiritual care specialists, such as chaplains, so that comprehensive follow-up assessment and care can be provided.

Chaplains are experts in providing direct and specialized spiritual care, including relief of spiritual suffering experienced by children and families. They also frequently facilitate family-staff communication, sometimes through attending case conferences or family meetings, and provide support, including spiritual support, to other members of the health care team (Lyndes et al., 2012). Other spiritual care specialists who may provide spiritual care to children and families while receiving healthcare include spiritual care providers from the community, such as priests, pastors, rabbis, and imams (Barnes et al., 2000).

Spiritual care, whether delivered by spiritual generalists (i.e., clinicians) or specialists (i.e., chaplains), may come in many forms, such as compassionate presence, deep listening, reading from Holy texts, talking about the divine and mysteries of the universe, or bearing witness to the events of a child or family’s life. Specific examples of spiritual care interventions have been highlighted in the pediatric oncology literature, and derive from complementary and alternative medicine. These include: therapeutic yoga, relaxation, hypnosis, massage, eurythmy (i.e., an expressive movement art), and mindfulness-based stress reduction (Geyer, Lyons, Amazeen, Alishio, & Cooks, 2011; Kanitz, Camus, & Seifert, 2013;
What is most important in providing spiritual care is focusing on the needs of the patient and family and allowing the child or family’s humanness and presence to be central (Baird, 2015). Self-awareness about one’s own religious or spiritual beliefs is also key when offering spiritual care to pediatric patients and families. Several studies involving pediatric clinicians note the influence of the clinician’s personal religious or spiritual beliefs on delivery of medical care to patients. In these studies, clinicians who felt religion and spirituality were relevant to pediatric outcomes, or felt capable of engaging religious or spiritual inquiries, or felt broaching religious or spiritual topics would not create negative responses were more likely to engage in religious and spiritual dialogue with patients and families (Armbruster, Chibnall, & Legett, 2003; King, Dimmers, Langer, & Murphy, 2013). While some studies report that just over half of clinicians feel personal/spiritual beliefs impact interactions with colleagues and patients (Catlin, Cadge, Ecklund, Gage, & Zollfrank, 2008; Ecklund, Cadge, Gage, & Catlin, 2007), other studies report that personal beliefs do not change actual care of patients (Donohue, Boss, Aucott, Keene, & Teague, 2010) or the likelihood that clinicians will discuss religious or spiritual issues with patients and families (Siegel et al., 2002). Also noteworthy is that those early in their career (i.e., residents) tend to receive more requests for prayer from patients and families and believe that engaging in prayer with patients is appropriate (Armbruster et al., 2003; Siegel et al., 2002).

**Areas Requiring Further Research**

Given the evidence, which shows that spiritual care is important to the health and well-being of a large number of pediatric patients and their families, further research, aimed at assisting healthcare teams in providing more robust spiritual care for this population, is warranted. Given the scarcity of measurement tools available, more provider-specific spiritual assessment tools, which address religious and spiritual needs beyond a western-Judeo Christian worldview and are specifically designed for children and adolescents, are needed, along with provider training in using these tools. Additionally, given the relatively few studies, which explore the role of religion and spirituality for ill children, further studies are needed to investigate how and why religion and spirituality play a role for patients in various pediatric settings, before interventions can be developed and tested. Finally, future studies could explore which members of the health care team pediatric patients and their families prefer to assess their spiritual needs and provide spiritual care. Developments resulting from these research endeavors will aid the health care team in providing quality spiritual care to pediatric patients and families during times of illness.

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NURSES AND SPIRITUAL CARE OF SERIOUSLY-ILL CHILDREN AND THEIR FAMILIES

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This article recaps two recent journal articles written about the spiritual care needs of seriously-ill children and their families. Previous studies have explored children’s and families’ struggles with serious illness, and the depression, grief, and emotional strain that accompany these struggles. With the growing movement of pediatric hospice and palliative care, researchers have begun to examine the spiritual dimensions of pediatric illness and have identified nurses’ lack of competency in communicating with children and families about spiritual concerns and experiences. Although communication training is now recognized as a vital part of nursing education, little attention has been paid to addressing spiritual needs in nurse communication training.

The authors of the above-referenced papers have been involved in two national nurse-training programs. The first is the End-of-Life Nursing Educational Consortium (ELNEC) project ¹, an international program that prepares nurses to care for the seriously-ill. ELNEC includes a specific program devoted to pediatrics. The second national nurse-training program is COMFORT ², a communication course that trains nurses on how to communicate with patients, families, and colleagues. In both training programs, investigators observed that nurses were least comfortable communicating about spiritual care. In order to facilitate more effective communication training for nurses caring for seriously-ill children and their families, researchers sought to identify the spiritual concerns of seriously-ill children and their families.

Nurses who attended one of three end-of-life nursing education courses conducted in the US in 2015 were asked in a questionnaire to relate in writing their experiences with seriously-ill children and their families, specifically the spiritual aspects of the illness journey. From the nurses’ responses, investigators identified spiritual themes common among ill children and additional themes that arose in interactions with their families. Investigators used experiences from an earlier study on communication regarding forgiveness³ to supplement the themes identified by nurses in their questionnaires.

Exploring the spiritual needs of families with seriously-ill children

It has long been recognized that a child’s serious illness profoundly affects a family’s physical, psychological, and spiritual health.⁴ Nurse’s responses in this research confirmed multidimensional family distress. Investigators identified four spiritual themes common in families’ struggles with a child’s serious illness. They were: anger with God; blame/regret; forgiveness; and ritual and cultural traditions.

With regard to anger, parents blamed God for letting their children get sick. In some cases, the anger caused families to abandon their faith. In others, the anger about the illness and at God caused family members to struggle and to question, driving them to seek new meaning through spirituality. The
expressions of anger exposed families’ spiritual struggles and need for support. The research revealed how properly trained nurses could help identify families’ needs for spiritual support and in some instances, assist in coordinating care by spiritual care professionals. Nurses also identified families’ need to express blame or regret, especially at a child’s end of life. Parents and family members often blamed themselves, questioning what they had done that had caused a child’s serious illness or why they had failed in finding a cure. Family members sought forgiveness from children and children from parents at a child’s end of life. In some instances, nurses reported that parents apologized to children for their behavior—being absent from their lives, not being honest about the child’s condition, or prolonging futile treatment. In other instances, it was the child who apologized to the parent for causing grief and sadness, a teenager finally admitting the drug problem and overdose that would lead to his death.

Rituals and cultural traditions played an important spiritual role in families, as their children faced end of life. Nurses reported the importance of recognizing and respecting a family’s cultural traditions, even when those traditions and a family’s wishes were at odds with a nurse’s own spiritual beliefs and traditions. Communication and cultural training are particularly important, as nurses will inevitably encounter cultural differences with increasing frequency in today’s multicultural society.

National guidelines in the US have identified spiritual care as one of the eight essential domains of quality palliative care. Families often draw on religion and spirituality, as they face the critical impact of a child’s death on their lives. Nurses are uniquely situated to hear families’ stories and witness their spiritual struggles, and with the proper training, identify families’ unmet needs, resolve conflicts, and coordinate care with spiritual care professionals.

Nurses’ experiences of spiritual communication with seriously-ill children

Although spiritual care is essential in pediatric palliative care, few providers receive spiritual communication training. In this portion of the study, nurses who attended one of three training programs were asked to provide written stories about spiritual conversations they had with seriously-ill children. Four major themes emerged: spiritual questioning; discussing the afterlife; descriptions of heaven; and hearing God’s call.

Nurses reported that seriously-ill children often had questions about faith and spirituality. Across the stories, children questioned why a “just” God would allow them to face the end of life. Often the question took the form of: “Why do bad things happen if God is good?,” “Am I going to die?”, or “What does God want me to do?” Nurses expressed that they were uniquely qualified to address a child’s spiritual questioning; of all the healthcare professionals, they were the ones that spent the most time with the child and got to know the child the best.

Nurses shared that children often expressed thoughts, visions, and dreams of an afterlife, that they would be joining friends or family, or that they had had conversations with people who were waiting for them on the other side. Children described vividly what the afterlife would involve, equating nature, sometimes butterflies or dolphins, to it. Nurses remarked that children discussed the afterlife without fear or sadness. They shared visions of heaven as a place of beauty, where they would await loved ones. Nurses commented that these spiritual communications gave parents comfort and a peaceful understanding that their child would not journey alone.

The nurses reported that children often spoke of hearing God’s call, being called to accompany God on a journey. Some asked their parents’ permission to go on the journey. Nurses stated that a child’s talk of God was influenced by the family’s culture, rituals, and traditions.

Nurses expressed that ill children had spiritual needs and that it was important to acknowledge these needs and experiences. A nurse noted that it was not important whether she believed in a child’s visions. Rather, it was only important that she listened and supported the child who heard the voices, believed in the angels or the afterlife, through dreams, visions, and audible calls. In “Nurses’ Experiences of Spiritual Communication with Seriously-Ill Children,” one of the two papers recapped herein, a nurse commented that spiritual communication with ill children was vital to “helping them across the river as gently as we
can.” She described the line between worlds as a “permeable membrane” or a “place of passage…an open door…opened a fraction of an inch…I have learned that each child’s spirit takes that step.” Nurses expressed that they needed only to be present with the children, spiritually available, and spiritually aware to guide them.

The nurses’ experiences illustrated the importance of communication skills to assess and respond to children’s spiritual needs, to provide comfort and support, as they and their families faced the child’s serious illness and/or death. The investigators concluded that it was vital that nurses be equipped with the training to listen, be present, and be mindful, and if needed, to respond to a child’s spiritual questioning or facilitate important discussions of heaven and the afterlife.

References:


In my role as a pediatric palliative care physician, I routinely find myself meeting with families and PICU colleagues, trying to determine the best course of action to care for a critically ill child. The ethical principle of “best interests” is meant to guide decision-making in these situations. Much of the time, all parties are able to reach an agreement, even when it leads to the decision to withdraw life-sustaining treatment and allow the child to die. But occasionally there are situations where the PICU feels death is inevitable, ongoing care is “futile”, and discontinuation of life-sustaining treatment is in the best interests of the child; yet the parents disagree.

The May 2017 “Trends in Pediatric Palliative Care Citation List” was filled with interesting new publications, but the one that most caught my eye was this article by Birchley et al. The focus of this study was how parents and staff make decisions in the Pediatric Intensive Care Unit (PICU), particularly in circumstances where the medical team recommends forgoing a child's life-sustaining treatment. Purposive sampling was used to recruit 14 parents and 15 PICU staff to participate in this qualitative study. Seven members from “clinical ethics committees” were also recruited, but unfortunately the findings from these interviews do not appear to be reported. The investigators found that parents and staff preferred making decisions together, but while parents believed that factors affecting the child should be the sole focus of deliberations, staff tended to consider the impact on the family. When disagreements were protracted, staff often gave parents more time so that their “feelings could adjust”; staff avoided turning to the courts as the ultimate arbiter of unresolved disputes.

Overall, I found the results of this study to be congruent with my own lived experience. Parental conviction that their child’s interests alone should guide decision-making is admirable, but unrealistic and even undesired in my opinion. Pediatric palliative care identifies the family, not only the child, as our unit of care; more often than not I have found that we are able to successfully take into account the interests of all. I was encouraged that PICU staff preferred to give parents more time, rather than turning to the courts, even when disagreements were prolonged. The emotional experience of witnessing one’s child not improve, and possibly deteriorate, despite best efforts of PICU staff is often more helpful to parents than recurrent family meetings or threats of legal recourse.

But one aspect of this publication did trouble me. The authors concluded that “alternatives to the consensus approach” may be needed in light of clinician reluctance to utilize the courts when agreement cannot be reached expeditiously. Moreover, the authors suggest that one such alternative would be to seek parental assent in these situations, as opposed to their consent. In other words, while parental agreement to forgo their child’s life-sustaining treatment would be desired, it would no longer be necessary.

Although the authors state that clinicians have “doubts regarding the efficacy of the legal processes” to resolve disputes (presumably in favour of the PICU’s position), this is not supported by the quotes shared in the article, nor is it consistent with Canadian case law (I am not familiar with UK case law where this study took place). Rather, the primary reason for avoiding the courts in my opinion, and as shared by the interviewed clinicians, is that a combination of patience, compassion and a trusting relationship with parents can eventually resolve most disputes. It may be that the authors are primarily concerned about the length of time to reach resolution. So let me ask – just how long should it take parents to accept their child’s death? Personally, I’m amazed at how often parents accept our medical recommendations to withdraw life-sustaining treatment after just a few days or weeks in the PICU. I think this speaks to the
deep trust that parents have in their child’s clinicians, whom they correctly assume also want the best for their child. Any unnecessary suffering by a child is unsettling, but we must remember that our own anguish is likely a fraction of that experienced by the parents. Fortunately, there is much that we can do to minimize the suffering of a child while resolution is being sought, and in my experience PICU clinicians are among the most skilled at ensuring a child’s comfort. Finally, the authors may be troubled by the unacceptable toll that protracted disputes place on the already limited resources of the PICU. However, despite the many times I hear this concern, I’m not aware of any published evidence to support it. Our own PICU in Toronto is regularly short on beds and staff, but never has anyone suggested to me that the cause was children being inappropriately kept alive on life-sustaining treatments.

Unilaterally resolving disputes with parents may facilitate a quick resolution, but the goal of medicine is not to make things easier for healthcare providers; the goal is to help those in need of our assistance. In pediatric medicine those in need are the child and the family.

This citation list is generated monthly by PedPalASCNET to collect new articles in pediatric palliative care research. To see past citation lists and expert commentaries visit our blog.


The spiritual needs of seriously ill children and their families. (2017). Nursing Children and Young People, 29(3), 27. https://doi.org/10.7748/ncyp.29.3.27.s25


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ITEMS OF INTEREST

In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. **NHPCO Palliative Care Online Resources:**
   NHPCO has a variety of pediatric hospice and palliative care resources available at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics). Also, more palliative care resources are available at [www.nhpc.org/palliativecare](http://www.nhpc.org/palliativecare), including:
   - Community-Based Palliative Care
   - Legal and Regulatory Resources
   - Webinars and Courses
   - Plus more for NHPCO members

**Palliative Care Programs and Professionals**
Join NHPCO Today!
[Individual Palliative Care Membership]
[Pediatric Care Group Application] - Save by registering your entire team

2. **Pediatric Hospice and Palliative Care Resources:**
   - **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. [www.caringinfo.org](http://www.caringinfo.org)
     - When Your Child is in Pain
     - Talking With Your Child About His or Her Illness
     - Talking to Your Child’s Doctor: When Your Child Has a Serious Illness
     - When a Child Dies: A Guide for Family and Friends
     - Helping Children Cope with the Loss of a Loved One

   - **NHPCO's Palliative Care Resource Series** now includes pediatric palliative resources such as:
     - Nonpharmacological Pain Management for Children
     - Sibling Grief
     - Pediatric Pain Management Strategies
     - Communicating with a Child Experiencing The Death of a Loved One: Developmental Considerations

   - **Center to Advance Palliative Care**: Did you know there are new tools to support your program? CAPC is pleased to announce the launch of three new resources for pediatric programs.
     - [Pediatric Palliative Care Survey in the CAPC National Registry](http://www.nhpc.org/pediatrics): Submit your program data now to generate individualized performance reports on program structure and operations, as well as comparisons to other pediatric palliative care programs. CAPC membership is not required.
     - **The Pediatric Palliative Care Field Guide**: A catalog of field-wide program development tools, support sources for field research, and an updated value statement to help programs make the case for pediatric palliative care resources.
     - **The CAPC Pediatric Palliative Care Toolkit**: A collection of new, practical tools and technical assistance for pediatric palliative care programs developed by leaders and experts across the country. Available to members now in CAPC Central.
• “A Perinatal Pathway for Babies with Palliative Care Needs” from Together for Short Lives in the U.K., developed in conjunction with ethicists and clinicians working across obstetrics, antenatal and neonatal care, and children’s palliative care. Full pathway available for free download via this press release and links here: http://www.togetherforshortlives.org.uk/news/11605_together_for_short_lives-launches_vital-resource

• Three Years ago Holland Bloorview Kids Rehabilitation Hospital launched the Chronic Pain Assessment Toolbox for Children with Disabilities. The Toolbox has received over 6000 downloads to date! Since then three eLearning modules have been developed. The modules will introduce you to:
  1. Chronic pain in children with cerebral palsy and the development of the Toolbox
  2. The sections of the Toolbox and how to start with based on your needs
  3. A case study of a complex patient from one of our nurse practitioners, and how a chronic pain assessment tool supported her clinical examination.

Check them out here: http://hollandbloorview.ca/Toolbox

3. Pediatric Hospice and Palliative Care Training:

• 3rd Annual PPCC Conference: Navigating Challenges in Pediatric Palliative and Hospice Care: Keynote Speaker: Dr. Chris Feudtner, PhD, MPH Director of the Department of Medical Ethics at The Children’s Hospital of Philadelphia and Director of Research for the Pediatric Advance Care Team and the Integrated Care Service
  Thursday, October 5, 2017
  The Desmond Hotel
  Malvern, PA
  7:00 - 8:00 am - Registration/Breakfast with Exhibitors
  Register Here

• Nationwide Children's Hospital in partnership with The Ohio Council for Home Care & Hospice 2017 Pediatric Home Care Conference:
  With a strong mission of promoting quality and safety of pediatric patients, the faculty members at Nationwide Children's Hospital are extremely committed to the pediatric education of medical professionals. You won't want to miss this one-of-a-kind networking opportunity to connect with other home and community-based care providers. Exhibitors will be available throughout the day to share information about their products and services for the home care and hospice industry.
  November 2, 2017
  7:30 AM - 4:30 PM
  Nationwide Children's Hospital - Stecker Auditorium
  More information here

• HPCANYS 2-Day Interdisciplinary Pediatric Palliative Care Training Unique to New York: The interdisciplinary team approach for both the child and family is what sets an excellent pediatric palliative care program apart. This training will focus on how disciplines overlap and support each other to provide optimum care for children at end of life.
  HPCANYS’ Pediatric Palliative Care training recognizes that all team members are an important part of the Plan of Care and each team member has something valuable to contribute.
  November 16-17, 2017
  8:30am—5:00pm
  The Sagamore
  110 Sagamore Rd.
  Bolton Landing, NY 12814
  Register Here
4. **Journal / News Articles**

- **Hospice at the age of 4**: “What I could not have imagined is that hospice would give us 18 beautiful months and that they would the happiest of my life.” Read more [here](#).

- **Shared Decision-Making and Children with Disabilities: Pathways to Consensus**: This clinical report provides a basis for a systematic approach to the implementation of SDM by clinicians for children with disabilities. Read more [here](#).

5. **Subjects and Contributors for Future Issues of This E-Journal.** For upcoming E-Journal issues, we plan to address issues related to: Perinatal/Prenatal Hospice & Palliative Care, and Concurrent Care/Waivers. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at ctorkildson@mail.cho.org or christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

6. **Reader's Corner.** Our Reader's Corner columns provide brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric hospice and palliative care, but that may not be known to readers. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles. Please send suggestions to Christy Torkildson at christytork@gmail.com.

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Children’s Project on Palliative/Hospice Services
ChiPPS serves as the Pediatric Advisory Council for the National Hospice and Palliative Care Organization.
Learn more at www.nhpco.org/pediatrics