Spiritual Care in Pediatric Oncology

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What is religious? What is spiritual? And why should we pay attention to these issues in healthcare?

There have been many efforts to define the two concepts of religion and spirituality. For instance, Harold Koenig defines religion as "an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred or transcendent" (Koenig et al. 2001). The Oxford English Dictionary begins with this focus on structure as well: "The belief in and worship of a superhuman controlling power, especially a personal God or gods; a particular system of faith and worship." This is often associated with an organized community where "worship" includes historic and/or traditional practices and beliefs and which has in common, with other organized communities, an authoritative text or narrative. Interestingly, there is a third definition that departs from this structuralism: "A pursuit or interest to which someone ascribes supreme importance." When defining spirituality, Koenig suggests that it is "the personal quest for understanding answers to ultimate questions about life, about meaning, and about relationship with the sacred or transcendent, which may (or may not) lead to or arise from the development of religious rituals and the formation of community" (Koenig et al. 2001). The Oxford English Dictionary similarly states: "Of, relating to, or affecting the human spirit or soul as opposed to material or physical things." Many of us in the work of providing spiritual and/or religious care to those who are ill or dying have our own idiosyncratic connotations, which typically revolve around the search for meaning, feeling to the world, to others, connected to something "greater than one's self."

Most believe that human beings are much more than merely the sum of their parts. We seek to find some meaning in who we are, to understand the relationships between our experienced reality and ultimate purpose. We want to "bind together" (the meaning of the Latin root word for religion) and "breathe" (the meaning of the Latin root word for spirituality) life and meaning into existence. On any ordinary day, we may be more or less concerned with these implications and more or less connected to our spirituality and religion. But when our vitality and health are diminished or threatened, the quest for meaning and understanding becomes much more an intrinsic part of our lives.

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Religion and Spirituality in Medical Settings

By 2010, more than 326 quantitative, peer-reviewed studies have examined the relationship of religion and spirituality with medical care. Of those, nearly 80 % found a significant positive association between religion and spirituality and well-being (Koenig et al. 2001). One important paper reported that nearly half of the persons who wished to have a discussion about their spiritual concerns with a healthcare provider were denied that experience (Williams et al. 2011). Another landmark longitudinal study with 444 hospitalized medical patients found an association between religious (spiritual) items patients struggle with and an increase in mortality, independent of physical and mental health (Barnes et al. 2000). The items are listed in Table 18.1.

Overall, the research supports the importance of religion and spirituality on several fronts: (1) Many patients and families are religious and/or spiritual and would like their faith addressed in their healthcare; (2) many patients and families have religious and/or spiritual needs related to illness that could affect mental health, but go unmet; (3) patients and families, during times of hospitalization, are frequently isolated from their supporting communities; (4) religious and spiritual beliefs affect medical decision making and may conflict with treatments; and (5) religion and spirituality influence healthcare in the community. Additionally, the Joint Commission expects religious and spiritual needs and desires to *not* be ignored in the healthcare setting (The Joint Commission, Standard R1.01.01.01).

Table 18.1 Patients Expressed These Concerns with Regard to Connections Between Their Illness and Their Faith/Spirituality

Wondered whether God had abandoned me [felt abandoned]
Felt punished by God for my lack of devotion [felt responsible for own predicament]
Wondered what I did for God to punish me [felt responsible for own predicament]
Questioned God's love for me [questioned lovability and worth/value]
Wondered whether my church had abandoned me [felt abandoned by or outside caring community]
Decided the Devil made this happen [attributed evilness of situation to outside influence]
Questioned the power of God [questioned concept of providence]

Religion and Spirituality in Pediatric Settings

An article in pediatrics titled *Spirituality, Religion, and Pediatrics: Intersecting Worlds of Healing* reported that religion and spirituality play important roles in shaping the way families live their lives and therefore may have broader implications for children's health (Barnes et al. 2000). This may impact everything from how parents seek healthcare for their children or turn to religious and spiritual healing therapies, to specific ways that children cope with multiple aspects of their health and illness or loss. Yet the paper noted that pediatricians and other healthcare providers may be uncomfortable addressing what they assess to be negative aspects of religion or spirituality affecting the health of a child, rather than the important and varied role religion and spirituality play in the ongoing well-being of a child and their family (Barnes et al. 2000). In a paper by Purow et al. (2011), it is noted that spiritual beliefs play an important role in providing comfort and support for children with cancer and their families.

Guidelines for integrating spiritual and religious resources into pediatric practice are listed in Table 18.2:

Children as Spiritual and Religious Beings

Most of the tools used to explore what is significantly spiritual or religious in a person's life are adult models. Children frequently experience their spirituality and religion both physically

Table 18.2 Guidelines for integrating spirituality and religious resources into pediatric settings (Barnes et al. 2000)

Anticipate the presence of religious and spiritual concerns
Develop self-awareness of your own spiritual history and perspectives
Become broadly familiar with the religious worldviews of the cultural groups in your patient population
Allow families and children to be your teachers about the specifics
Build strategic interviewing skills and ask questions over time
Develop a relationship with available chaplaincy services
Build a network of local consultants
Refer to family-preferred spiritual care providers
Listen for understanding rather than for agreement or disagreement

and temporally; for them, this is not so much a cognitive construct or a rational explanation of the irrational as it is purely experiential. Children will respond to their experiences from within their developmental capacity. Spirituality at every age can be transforming as well. Therefore, it is important to have some basic understanding of what the basic developmental tasks, strengths, and distresses are of each major age group.

The Spiritual Life of Young Children

For preschoolers (ages 3–6), awe and trust remain a large part of their experience, but storytelling is becoming compelling for them. They begin to take some responsibility for family rituals such as prayers at meal or bedtime; they will initiate them, remind elders when they haven't been observed, and are very intrigued with creating their own rituals. If they are learning the stories of their family's faith system, or the stories of meaning as the family makes meaning, they are able to retell the story, insert themselves in it, and change it to make sense of their particular world.

Case Vignfoette

Christopher, a 4-year-old boy with a brain tumor, wanted the chaplain to read the story of David and Goliath every time she visited. For several days she simply read the story and observed that Christopher became calm and focused during and after hearing the story. His mother was very anxious and afraid to take a strong role in giving her son medications or helping with his mouth care. Christopher had learned his regimen and saw to it that it was followed. He appeared to percevie himself as David facing the Goliath of his disease. Not only did he "live" this story, he was able to articulate it when the chaplain asked him what he liked most about it. "David was very brave, even when other people were afraid [perhaps like his mother?]. He said to Goliath, 'you can't beat me' and he believed it."

The Spiritual Life of School-Age Children

When ill or hospitalized, the young school-age child (6–10-year-olds) can feel the sense of letting one's team down, one's parents down, and one's self down. A child also may come to feel that he or she has let down his or her religious and spiritual community. For example, some faith traditions place heavy obligations on members for their own healing ("If you have enough faith, you will be healed"), are intolerant of sincere expressions of fear or doubt ("You aren't supposed to question God," or fixate on a higher power that is overly punitive. This may compound a child's feelings of shame and guilt.

The child may live in two separate worlds. One is a logical, "schooled" world of work, organized play, and peer involvement. The other is a private world of imagination, which is still largely mythical and analogical. These worlds are not

contradictory for school-age children; rather they are examples of how children experiment with both sides of their brain as they seek a way for logic and myth to be combined and recombined. They use stories to gather and shape their fantasies.

Case Vignette
A chaplain was visiting with Steven a 7-year-old boy with Ewing sarcoma and they talked about the story of Jonah and the Big Fish. As they speculated about Jonah's thoughts and feelings, Steven made connections to his own experiences. He understood what it felt like to be in a scary, isolated place. He recognized the fear that goes with being carried along on a journey he did not choose, the outcome of which is uncertain. He knew that, in a situation like Jonah's, one might just wonder what God is up to.

For the later elementary to middle school-age child (11–13 years old), this is a time for rites of passage: for example, first communion, confirmation, youth group, and bar/bat mitzvahs. In addition, the symbols of the faith community have real power and majesty: the ark, the Cross, and the Qur'an. Children use these symbols and turn them over, not only in their hands but also in their psyches, looking for meaning and/or imbuing them with special authority and effectiveness as the following case illustrates.

Case Vignette
In the oncology playroom, Robert, a 12-year-old Christian boy with sarcoma, was fashioning popsicle sticks into an "X" shape on top of a square piece of foam. The chaplain said,
"Hi, Robert. What are you making today?"

"Don't you know what this is? It's a God-thing!"

"A God-thing?"

"Yes. Where they put Jesus and he died."

"Oh, a cross."

"Yeah. He died."

"That's true."

"They put nails in him."

"That's true, too. It must have hurt a lot."

"Nope! He could get away anytime he wanted!"

Prayers, rituals, blessings, and even cursing can be very powerful for school-age children. Salma, an 11-year-old Muslim girl with rhabdomyosarcoma, was in the hospital during Ramadan. Although younger than the required age for fasting, she wanted to participate in the daily fast. It was a spiritual discipline that she felt deepened her relationship with Allah and increased her potential for healing. Nutrition services were concerned about her health and did not want her to fast. The chaplain met with Salma and her parents and nutritionist to create a plan that would honor her religious beliefs while meeting her nutritional requirements. The team agreed that if Salma was willing to take liquids during the day, she could eat a meal before dawn and after dusk and still meet her nutritional needs.

School-age children judge very quickly and may want people to be punished for breaking the rules of justice as they perceive them. This plays out spiritually when a child feels that God isn't playing fair and should be held accountable. It is important for spiritual caregivers to listen to the questions and comments of the ill or dying child. It is often more vital to listen than to talk. Children in this age group will ask questions about matters they want to understand. They are not necessarily "comforted" by being put off or given "nice" answers. They can also have "unfinished business." It may be as simple as a school project or as complex as making up for some real or imagined fault. These are all spiritual tasks.

The Spiritual Life of Adolescents

Decision-making is based on what the adolescent considers important. This is very much a part of their spiritual character and struggle. There is a great deal happening in an adolescent's life including navigating family, friends, school, society, media, and technology and perhaps religion and spirituality. If spirituality and faith are going to have meaning for the adolescent, it needs to be in a way that helps them organize their worldview and establish their own identity.

Often, the experience in personal relationships drives how adolescents perceive unifying values. Teenagers will often be drawn into faith and spiritual groups because of defining values which seem utopian to the adolescent or, if not utopian, certainly pervasive and "true." The lure of cults can be very powerful during this developmental stage. These values simply "are" to the adolescent and they frequently do not examine them closely or reflect upon how they "work" or do not "work" in their lives or in the world. Teenagers develop ideologies they may hold to with determination. When they disagree with the values of another, it is often perceived as a difference in the sort of person one is and not based on a difference of ideas. Adolescents will identify and adhere to authority that they deem to have personal worth or is valued by their peers. A spiritual challenge faced at this age is that the expectations and evaluations of others, the values themselves, and the traditions either from the past or created specifically to meet adolescents' needs and desires can become so internalized, even made sacred, that their personal autonomy, judgment, and drive to act might be jeopardized. Also, any betrayal by a "worthy" authority or peer can lead to despair.

Physical changes that result from illness or injury can also lead to profound spiritual distress, though the underlying spiritual issue may be masked by an obvious physical concern. Adolescents receiving chemotherapy are often traumatized by the physical changes they anticipate and undergo. Teenage girls frequently voice special concerns about hair loss. This may be for them a spiritual dilemma as well as a physical one. A fear of feeling "different" or "embarrassed" in front of peers is real enough. But sometimes the distress is rooted in spiritual questions: "Am I still the same person I was before this change occurred?" "Am I more than my body?" "To what degree has the love and acceptance I've known been related to my appearance?" As they anticipate hair loss, many adolescent girls seek out natural-looking wigs; at the time certain they will never allow themselves to be caught without it. But later, many girls lay the wigs aside to walk proudly, and baldly, into the world. Perhaps the underlying spiritual questions have been answered. "I am a loved and valued person because of who I am and not because of how I look." "I have supportive and loving people in my life, no matter what."

Even during times of spiritual dissonance, seriously ill adolescents can survive with strength and purpose. This is particularly true if they have a sense of personal power that they have some control over things that are occurring, a sense of purpose that life has meaning, and a sense of optimism regarding their own future. Adolescents may be very interested in providing some sort of legacy, not only for their families but for the "world." One teenager organized an art show on her inpatient unit and arranged for hospital leadership to come and judge the art in several categories. The projects were sold and the patient arranged for the proceeds to fund a juried art show every year on her birthday. Teenagers want to know that their life matters and that they are able to accomplish something and can make a difference in the world. These are human needs, but they are also spiritual needs. Faith and spirituality give us a sense of place and purpose not only as individuals but as participants in something much larger and much more eternal than ourselves.

We have several tasks as caregivers. One is to participate and legitimate the adolescent's search for meaning and not to tell them what it is. Another is to respect the struggles, the ideas, and the hard work in which adolescents are engaged. And a third is to empower adolescents to find and use their own voice. It is our task, as well, to assist adolescents in developing spiritual health. We are able to do this one on one with the

adolescent and within the teenager's community. We can offer a variety of ideas for consideration as well as share doubt, particularly when cure is no longer possible.

Adolescents have a much more adult understanding of death and dying in terms of what occurs biologically and how living and dying are interwoven. But they may be confused about it theologically, emotionally, and socially. Some of their understanding and lack of understanding come from prior experiences with death as well as the teaching in their family and community.

As adolescents approach end of life, they often need supportive listeners who will sit patiently while they grieve the lives they will never have. In contrast to older adults at end of life, adolescents mourn not only the relationships and experiences they leave behind (both good and bad); they mourn a future that will not be realized. Teenagers often voice deep sorrow that they will miss opportunities to graduate from high school or college, engage in romantic or sexual relationships, experience the adult world of work, or become parents and grandparents themselves. One adolescent said of his life, "There are so many things I haven't done. I don't feel whole."

It is important for adolescents who confront their own mortality to identify connections with their own family's faith stories, if they have them, especially if doing so can facilitate a feeling of peace or reassurance. At the same time, they must be allowed to voice the questions for which there are no easy answers, no matter how uncomfortable they are to hear.

Some adolescents who are dying will want to spend as much time as possible with their peers and it may be their friends who participate in discussions with them about dying and about what the adolescent believes and hopes.

Models of Children's Spirituality and Religious Consciousness

Children express their spirituality and religious consciousness very naturally. Often we see instances of this in their day to day lives through their actions and their narratives and in their sense of belonging to family, community, God, and the world. Children show us or tell us how they feel thankful and the ways in which they feel safe and loved. Through their rituals (either formally or personally), we learn that they believe they have what they need to live and that there is, or is not, someone who cares for them. Sometimes, children will want to be very active and demonstrative in the ways they contribute to the goodness of the world such as sharing a special toy with a friend who may be ill or participating in a fundraiser for their specific type of cancer. Often times, children express their specific understanding of their own spirituality and religious consciousness.

Case Vignette

Upon learning of his diagnosis, Lucas, a bright, articulate, and faith-knowledgeable 7-year-old boy with osteosarcoma, asks to see the chaplain. Lucas wants to know why God would let something so horrible happen to him. Over several days the chaplain visited Lucas and they talked about many things, including God. Together, they explored the God Lucas had come to know and believe in. One afternoon Lucas was able to express his own answer. He told the chaplain that God must have been very busy the day Lucas got sick – maybe holding up an elephant in one hand. If God had to drop the elephant in order to prevent Lucas' bones from getting sick, then the elephant could have been seriously hurt. God had a hard decision to make and God must have known that Lucas and his family were going to be all right but the elephant would have died if he dropped him.

Lucas was expressing not only his own belief in a God who is complex but operates in a meaningful system of love, trust, and care. Often through a child's play or stories, we see children's strength in their spirituality and religious consciousness, as well as in the way they demonstrate

hope and perceive the future and their own and the world's future (Yust and Roehlkepartain 2009).

Mark Tobin published a book called *The Secret Spiritual World of Children*. Along with his theoretical discussion, he collected stories about children who wonder, who listen to wisdom, who are deeply embedded in relationships and the "lovingness" between themselves and another, who are curious, and who see beyond the physical to the spiritual planes (Tobin 2003). In his chapter regarding wonder, he begins with this story: A man and his 8-year-old daughter were at the beach where he watched her for over an hour as she just stood in the water up to her waist, swaying gently in the surf. It was nearly an hour and a half before she came out of the water, absolutely glowing and peaceful. She sat down next to him without a word. After a few minutes, he managed to gently ask what she had been doing. "I was the water," she said softly. "The water?" he repeated. "Yeah, it was amazing. I was the water. I love it and it loves me. I don't know how else to say it." They sat quietly until she hopped up to dig in the sand a few minutes later. "Somehow I felt completely overwhelmed, like I had witnessed grace," the father said.

Many things influence the development of spiritual and religious consciousness in children. Foremost are family and community, what is taught and what is expected. We cannot make assumptions or judgments about how children will develop their religious and spiritual identities. Children in great need may seek meaning and purpose in different ways. Each child must be approached as a unique being.

Joyce Ann Mercer, a professor of pastoral theology, proposes four categories of children's spirituality: mystic, activist, sage, and holy fool (Mercer 2006). The *mystic* child is one who seems deeply in touch with the numinous and who describes encounters and memories of being with and connected to their Holy One. They understand that the world is mysterious, there are possibilities far beyond anyone's ability to comprehend, and the boundaries between "real" and mystical are fluid and permeable. *Activist* children live out what they believe either through their social awareness or kinesthetically. An activist child may be involved in helping endeavors with school or family, visiting the elderly, and giving away items either of their own or collected on behalf of others. These children may also feel most alive and connected when engaged in physical activity.

The *sage* is the wise-beyond-one's-years child. They practice deep compassion and make connections between other's stories, their own story, and Holy stories. They do not hesitate to say what they perceive or experience and frequently take for granted how exceptional their insights are. Emma, a 4-year-old, was one such sage. One afternoon, when Will, her 2-year-old brother was within a few days of dying from a brain tumor, Emma sat with the chaplain to read books and paint. The chaplain said to Emma, "I wonder what you know about what is happening with Will." Emma, who had been mostly quiet during the encounter, said "Look." Taking a sheet of paper, she planted a fat dot of red paint in a corner. "This is Will." Next to that, she painted a circle. "This is God. And God is dreaming of Will." Even at 4, Emma felt reassured by her belief that there was a Will-shaped space in God and that Will and God were somehow connected in a relationship of dreaming and wonder.

Last, in Mercer's metaphorical categories, is the *Holy Fool*. They are the children who speak the truth lovingly – but truth it is. Others may simply perceive these children as "cute," but they are much more. For example, Melissa, a 6-year-old with ALL, was being teased at Sunday school about the loss of her blond curly hair. Melissa remained calm and said to the other children "my hair will grow back because it is a gift from God." When the Sunday school teacher laughed at her "cute" response, Melissa was surprised and said "but you are the teacher and you should know about God" (Mercer 2006).

Another model for children's spiritual and religious consciousness describes four dimensions of relationship: God/transcendence, others, world, and self. These point us "to spirituality as concerned with the deepest levels of human experiencing, the places of ultimacy, value, and deepest meaning in and for our lives"(Hay and Nye 2006).

Children have an intuitiveness that helps them connect on the subliminal level. Many psychosocial clinicians will describe some of the children they have worked with as "old souls." Some children display this characteristic more deeply than others, but we believe all have the potential for accessing wisdom that is beyond their years.

Thinking about Spiritual Interventions with Children

It is the work of the entire care team to respond not only with the best physical care for children but also with sensitive emotional, spiritual, and religious care. It is important to discover the child's own unique religious and spiritual consciousness and also to provide opportunities to grow and nurture that consciousness. Children intuitively feel awe and delight. We can observe it in the newborn who catches sight of sun and shadows playing tag on the wall. As children develop, they see, hear, and experience mystery in their relationship to nature, to others, and to themselves. As they grow, learn, imagine, and practice what it is like being themselves as distinct, unique individuals in a world with other unique, distinct individuals (as well as a few inanimate, animal, and mythic realities), their concept of the numinous becomes healthier and more universal. It is important for the psychosocial clinician to remember that for children the world is bigger than a particular event or illness and usual children's pleasures such as laughing and playing still exist. Helping a child remember, plan, and enjoy what is possible is a spiritual endeavor.

Children will sometimes declare that they have had conversations or connections with God. For example, one young child shared, "God just talked to me! It was so wonderful; quiet and warm. It felt like being wrapped up in my fleece blanket – only I wasn't hot. We held hands – he said even if I was very afraid of my medicine and treatments that sometimes he would know, and would be near to help take care of me." Older school-age children often experience transcendence and awe very kinesthetically, as noted earlier in the story of the child standing in the ocean "becoming" the water.

Table 18.3 Ways to explore what the child with cancer wonders about

I am going to draw a picture of something that makes me feel safe; can you draw one, too?
How long is time?
Tell me about one good thing
Tell me about one scary thing
Who do you feel blesses you?
How do you bless others?
If God, Jesus, Allah, etc., were sitting here with us, what do you think he or she would say to you? What would you say to him or her?
I'd really like to know what you think heaven is like
What is the most wonderful thing in the world?
What is perfect?
Can you describe yourself just with colors? (then – what part of you is red/black?)
I like the sound of or don't like the sound of…. What sound do you like, or don't like?
Do you have a special word you like? How does it make you feel?
Would you like to have someone pray with you?
If you could go one place right this minute, where would it be? Why?
When I feel sad, I cry or go off by myself. What do you do when you feel sad?
Can you tell me one thing you feel sorry about?
Sometimes I get really mad because…. Do you ever get really mad?
What is your favorite book, movie, etc.? (Then explore the spiritual themes in it)

When we are attempting to help children and adolescents nurture and articulate their religious and spiritual consciousness, psychosocial clinicians must be attentive to being with the child and not merely visiting or carrying clipboards with a research questionnaires or screening forms. This "being with" is important so that we may differentiate the child's religious and spiritual consciousness from that of their parents and family. The values, beliefs, and needs of each may be very different. Table 18.3 provides ways to open conversations about spiritual matters. When you are considering how to bring to the surface a child's thoughts about faith, or blessing, or one of the other spiritual categories, conversation starters listed in Table 18.3 may be of help.

We can assist children in talking about what they find awful by being patient and by asking

open-ended questions and statements, bringing pictures or books, and watching videos or movies. There is a godly talk opportunity about almost anything in which a child has some interest.

Case Vignette
A chaplain, watching the movie "Neverending Story" with a young patient receiving treatment for leukemia commented on how extraordinary the author's imagination was and how sad a world it would be if imagination disappeared. The child responded "That would never happen – people will always imagine wonderful, good, sometimes bad, things; they will search, because they need to, for different ways to tell us the same stories about how evil almost overcomes good, but that good always triumphs in the end. And besides, God gave us freewill."

Sometimes children will want to talk about their relationship with the one they call God, or Allah, or Yahweh, or another deity. Patience and the willingness to listen without correcting or questioning too directly can give us significant insight into how children experience the values and teaching of family and community and what they understand, accept, and reject. It is not our job to fix what we may hear as a faulty theology; rather it is our job to listen to the child's theology and words and stories. If the child is troubled, it may be important for them to share their questions and their philosophic explorations with a family member or compassionate leader of their community.

Children can tell us about what they feel, or have experienced, as good and bad and how those are balanced in their lives; they can tell us when they feel as if they have some control or no control. It is important to explore with a child their locus of control. If it is all external (e.g., God, parents, family, and doctors), they may feel helpless and anxious. However, a locus of control that is primarily internal, that is, that the child typically has a sense of being powerful and in charge, can also lead to feelings of helplessness when they are unable to change their circumstances.

As caregivers, we also need to examine our perceptions and expectations about our relationship with the universe. If we are unclear, it will be considerably more difficult for us to open ourselves to the unique ways children express their religious/spiritual consciousness.

Several other spiritual and religious consciousness components are also valuable to consider: faith, gratefulness, repentance, communion, and vocation (Pruyser 1976). Faith is both the ability children have to describe certain precepts of what they believe about God, life, and death and rules for living and their ability to communicate to us whether they feel that life has some intrinsic value. Does living and the experiences garnered in life mean something? Does it mean something to someone or something greater than one's self? Do they perceive life as an "adventure" or as a commodity to hoard? Both are spiritual responses; the spiritual is never merely the positive side of one's experiences or perceptions. What is spiritual, and/or religious, in our lives either opens up possibilities or closes them to us. When we work with seriously ill children, we need to gain an understanding of where they are on this continuum. Our work may be to draw them closer to the open end of spiritual/religious experiences and perceptions, or it may be to stay with them exactly where they are and help to make their closed life experience more tenable.

Human beings of any age typically wish to feel blessed and that they are a blessing to others, in other words: they wish to experience gratefulness. Certainly this is true of children who are sick. They want to know they are loved and that they deserve being loved even if they are not perfect. Children who can accept that they are agents in their own lives, even creating some of those things they dislike, are typically more open to seeing how they are and are not responsible for their current situation.

An important work of spiritual consciousness for children of all ages that becomes increasingly significant during adolescence is the ability to gain insight into one's own shortcomings, mis-

deeds, and hurtful impulses. Caregivers often must prompt young children to consider the negative impact of words or actions and remind them to "say sorry." Teenagers often do not need prompting to feel regret for the ways they have hurt other people, but may brood over feelings of shame or guilt in silence.

Case Vignette

Philip, a 19-year-old with a terminal brain tumor, had spent much of the previous 5 years incarcerated in a juvenile facility for gang-related activity. Reflecting on his life, Philip was grief stricken by the damage his early and persistent involvement with a gang had done to himself, to his family, and to many others who crossed his path. He expressed his shame and sorrow to his chaplain. He was sorry he had disappointed his mother, had not been able to have a close relationship with younger siblings, had bullied other young people at the juvenile facility, and had "wasted" his life. He did not believe that God could forgive him. He expressed little hope for finding peace before he died. Through spiritual support and counseling, Philip was able to participate in a ritual of repentance, naming explicitly the causes of his sorrow and accepting the forgiveness offered him by his family and by his faith. The process helped Philip move, in his final months, from feeling helpless before his human failings to a position of hopefulness and even joy in relationships restored.

Communion and vocation are the experiences children have of being a part of a community, having a role to play, feeling that they are part of the "circle of life," and how they participate in those roles. All of these concepts are intertwined in myriad ways. We are engaging children and adolescents around the ideas of being involved or uninvolved, of seeing mostly possibility and safety or mostly negation and danger, of having purpose or being out of control, and of continuity or discontinuity with all life, all meaning, all purpose – and everything along these continua. When children are seriously ill, these are extraordinarily important aspects of their ability to understand what is happening, to be able to describe for themselves why it is happening, and to feel that they can have some choices that matter desperately to them.

Conclusion

Each member of the psychosocial team has a role to fill in meeting the spiritual and religious needs of children who are diagnosed with cancer. Employing critical thinking and one's own unique skills, combined with openness and curiosity as well as deep regard for what children perceive and believe, is the starting point. Physical and psychosocial development and spiritual development are often established along similar trajectories. However, with children who are seriously ill, spiritual development frequently progresses more dramatically.

Clinical Pearls

- Many patients and families are religious and/or spiritual and would like their faith addressed in their healthcare.
- Many pediatric patients and families have religious and/or spiritual needs related to illness that could affect their mental health, but go unmet.
- Patients and families, during times of hospitalization, are frequently isolated from their supporting communities. Religious/spiritual beliefs affect medical decision making and may conflict with treatments.

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