Spirituality and Caregiving in Pediatric Illness



🕑 Learning Objectives

After reviewing this Guide you will be able to:

- Consider your spirituality and how it supports you
- Identify symptoms of spiritual distress in yourself and/or your child
- Determine ways to advocate for your and your child's spiritual self

Introduction

Virtually any crisis, including and perhaps especially that of having a child with a serious illness, stirs up many kinds of questions. Some parents coping with their child's illness find themselves in a crisis of faith, striving to understand why the illness has occurred and what can be done to change the circumstances—to make things "right." Others find that their faith is strengthened as they invest trust in something outside their control; they may even feel that they are being tested and must respond in faith. Some who have never had a faith system seek one; others reject their faith out of fear, anger, despair. There is no one way to experience the spiritual. For the purposes of this Guide, spirituality is defined not as faith, but as the expression of the universal human need to make meaning and to create a purposeful life.

Spirituality and Meaning

URAGEOUS

Meaning is at the center of how we live; it is related to our need to find and keep hope, express love and feel connection. Spirituality can be understood as our individual sense of what is meaningful: connectedness to self, to family, to community, to work and/or to something beyond-the "Divine," a power beyond oneself or an energy that does not end. Spirituality is our inner life, part of all of us and also different for each of us. And how we express spirituality is unique to each of us; it may be through going to a place of worship, rituals, prayer or meditation, connection to nature, artistic endeavors, or simply a feeling of the presence of something beyond our day-to-day reach.



(continued)



In thinking about your own spirituality you may find these questions helpful:

- Where do you find strength?
- What beliefs, practices, traditions and/or rituals bring you peace or meaning?
- What experiences bring you closer to your spiritual self?
- How do you recharge or refuel when you are feeling spiritually depleted?

Spirituality and Religion

Religion and spirituality overlap but are not the same. Religions are associated with institutions, doctrine, history, specific traditions, rites and rituals to acknowledge, worship, practice and communicate with the divine or sacred. Catholicism, the Protestant sects, Judaism, Islam, Baha(i), Hinduism and Buddhism are examples of religions. Spirituality is an aspect of most religions; however, religion is not always a part of spirituality. Not every-one is religious, but virtually everyone experiences some aspect of the spiritual.

Spirituality in Children

The spiritual life of children develops over time. In early childhood, their understanding is typically based on what their parents believe and practice. Stories become a way for children ages 5-10 to explore spiritual issues. Children ages 10-13 may have questions about why bad things happen. Teenagers are thinkers who ask questions but may not have yet the emotional maturity to cope with very difficult situations.

The Role of Spirituality in Illness and Spiritual Distress in Caregivers and Children

Diagnosis of a serious illness–especially in a child–challenges our sense of the natural order of things. The prospect of a child's suffering challenges the belief that if we are "good," as innocent young children are, then all will be well. It challenges our perception of being in control. A devastating diagnosis also demands awareness that some things cannot be explained and that the future is uncertain.

Spiritual distress is perhaps best understood as inner "soul-deep" suffering that is not physical suffering. It is not limited to people who identify with a formal faith tradition or religion. Spiritual distress is commonly experienced as a struggle between what we believe, or wish, and what is occurring in our life. During times of crisis, it is natural and human to want to make some sense or meaning out of our situation. When one's current system of meaning-making cannot provide answers that feel authentic, one's faith can feel broken beyond repair. As one Courageous Parents Network mom said, "I don't know what I believe in any more." This all can feel extremely distressing.

(continued)

Symptoms or feelings of spiritual distress can include anxiety about dying and the afterlife; feelings of regret about the past or unresolved conflict; feelings of loss of purpose and meaning; questions about the meaning of life; and/or feelings of isolation and abandonment from one's family, community or a Higher Power.

Just as parents may experience spiritual distress, so too can children. Spiritual distress can affect their sense of identity, of their place in the world, of their sense of security. How distress in a child is expressed depends on their developmental stage and neurological status, and can change over time. A child's distress may be evident in their behavior: being anxious, angry or withdrawn. Their distress may affect their perceived pain level and contribute to difficulty sleeping. If you sense your child is experiencing spiritual distress, it is important to give them opportunities to explore their feelings. A spiritual care clinician or other trusted member of your child's team (see the section **Sources of Spiritual Support**) can assist you in determining how to help the child express their feelings and concerns.

It is important to note that other members of your child's family and close community– grandparents, aunts and uncles, friends, neighbors–may have different spiritual beliefs and traditions and practices which may or may not be helpful to you and your child. You may need assistance from a third party to help you navigate with others. The important thing to keep in mind is that everyone is entitled to their beliefs, and you are not obligated to hold or follow others' beliefs for yourself or for your child.

Sources of Spiritual Support

Parents and family members may seek solace in their faith traditions, including the rituals that are part of these traditions. Just as family history and culture influence decisions and coping, so might your religious upbringing or spiritual connections influence your values and beliefs. Adults who may be non-practicing in their religious beliefs often find that recalling sacred stories, family traditions, beliefs and practices from one's childhood can bring new insight to the present crisis of meaning and belief. The natural world (perhaps a park, the woods, a water view) and creative expression (writing, art, music, movement) are other possible sources of support and comfort.

If your child is receiving care in the hospital or community care setting, a spiritual care clinician or chaplain can help you and your child explore the spiritual dimension of the illness and manage any distress. These Board-certified clinicians are part of the multi-disciplinary team at most major medical centers and can work with you regardless of your particular faith practice, or lack thereof. They are trained to be present and compassionate with each person during the scariest and most threatening of times. Practicing active listening and accompaniment, rather than trying to persuade, judge or teach particular beliefs, is what they are trained to do. Their hope is to help bring you and your child closer to a sense of spiritual peace.

(continued)



Advocating for Your Spiritual Beliefs

What do you want clinicians to know or ask about? Consider the questions in the section **Spirituality and Meaning**. Do your beliefs guide your decision-making? Does spirituality or faith play an important role in how you or your child cope with difficult situations? Are there places where you can go to find peace and strength to move forward as your child's advocate? Are there spiritual advisors with whom you would like to think things through?

Your clinicians would like to know this, so that they can support this dimension of your caregiving and coping. However, clinicians may not ask you about your spiritual life unless they are chaplains or otherwise trained to treat people's spiritual needs. If your spiritual life is important to you but you are not asked about it, be sure to speak with your child's team. You do not need permission to talk about what matters to you and your family. Sharing this aspect of yourself can help you feel understood and is beneficial to everyone.

Here are some suggested conversation starters for discussions about spiritual values:

"My faith tradition is important to me and guides me in how I make decisions."

"I would like opportunities to speak with someone about my spiritual beliefs and values."

" I find spiritual support in my church/temple/community of friends/nature/art studio/etc."

"My spiritual advisor is someone I like to speak with to help me make decisions for myself, my family, my child."

"My spiritual practice is to pray/meditate/,/attend religious or community services or programs/exercise/paint/sing/play music/etc."

Conclusion

Traditional Western medicine has typically treated the physical self as separate from the spiritual one. The result has often resulted in fragmented rather than holistic care–but this is changing. Treating the whole child and family, which is especially the domain of palliative care, facilitates optimal medical care. So, as caregivers seek to advocate and make decisions for the child, they have the opportunity to be forthright about how their spirituality and/or religion influences and informs them.

Sources:

Waldman E., and Bartel M., Existential Suffering and Distress (Interdisciplinary Pediatric Palliative Care; Second Edition 2022. Joanne Wolfe, Pamela S. Hinds, and Barbara M. Sourkes; pp 245-252)