

Assessing and Responding to the Spiritual Needs of Seriously Ill Children and Their Caregivers



Learning Objectives

After reviewing this Guide you will be able to:

- Appreciate signs of spirituality in patients and caregivers
- Identify symptoms of spiritual distress
- Normalize spiritual assessment into Review of Symptoms (ROS)

Introduction

How do clinicians care for their patient’s whole person—physical, emotional, social, spiritual—and their caregivers? If illness is seen as impacting not only the body but also the spirit, then spirituality may be regarded as a fundamental element of wellness and healing. Incorporating a response to the spiritual needs of a child and their caregivers can be a meaningful aspect of family-centered, “palliative-aware” care. This role need not only fall to chaplains.

Definition

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 each of us and also different for each of us.

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. It includes a belief in something greater than oneself.

Sources of spirituality may be family, relationships, nature, religion, love, music, art or a mission or purpose in life. For some, compassion is spirituality in practice.

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Recognizing Spirituality in Patients and their Caregivers

Patients and caregivers provide information about their spirituality in statements like “I have a strong faith.” “I believe everything happens for a reason.” “I meditate/chant/pray each day.” “God’s / Allah’s will be done.” “I / my family am(is) being tested.” “I feel at peace when I hold my child at night.” Spirituality can also be recognized in questions like “Will you pray with us?” or “Do you believe in miracles?”

The clinician’s role is to support children and caregivers in their spirituality: to honor their beliefs and practices as expressed, and to be open to learning from them. Caregivers do not want to have their beliefs or practices questioned or challenged. They want and need respect, and the team’s willingness to support them in the stressors of decision-making and living with a child who has a serious illness.

Assessing Spirituality as Part of the Review of Symptoms

Pay attention to personal artifacts and belongings. What images are on the walls? What things are in the crib? What books are on the bedside table? What is displayed on the windowsill?

Work with an established assessment tool such as FICA© and/or HOPE.

- FICA© Spiritual History Tool
https://gwish.smhs.gwu.edu/sites/g/files/zaskib1011/files/2022-08/v2_fica_pdf_2_final_updated_6.29.22.pdf
- HOPE Spiritual Assessment Tool
<https://www.aafp.org/pubs/afp/issues/2001/0101/p81.html#the-hope-questions>
- Anandarajah G, Hight E. “Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment.” *Am Fam Physician*. 2001;63(1):87
<http://appd.s3.amazonaws.com/docs/meetings/2019SpringPresentations/ELS5HO1.pdf>

As these tools were developed with adult patients and their caregivers in mind, this language might help you in the pediatric context:

- Do you have a faith or spiritual beliefs that help you cope in difficult times? After a pause you may want to offer prompts: Prayer? Meditation? Yoga? or ask, What do care most about in life?
- What are your sources of hope, strength, comfort and peace? What do you hold on to during difficult times?
- Do your beliefs or practices affect how you are able to care for yourself/your child in this situation?

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- Are you part of a spiritual or religious community, such as a church or neighborhood or youth/adult support group? Does this connection help you? Would you be willing to tell me about it?
- How can I honor and incorporate your beliefs into [your child's] health care?
- What can I do to help you access the resources that usually help you? How can the team support and incorporate your beliefs and practices into the medical care you would like us to provide?

Spiritual Distress

Spiritual distress is perhaps best defined as inner, “soul-deep” suffering that is not physical suffering. It is not limited to those 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 actually occurring. Clinicians can recognize spiritual distress when a child or caregivers ask, “Why me / us / them?” or ask questions about the meaning of life or of pain and suffering.

A child’s medical crisis may prompt a range of responses from children and their caregivers, including:

- Questioning their belief system or spiritual (and/or religious) practice
- Expressing guilt about past or present actions
- Worrying about disappointing loved ones or one’s Higher Power
- Feeling angry, abandoned by, alienated or betrayed by one’s Higher Power or belief system

Just as caregivers 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 that a child may be experiencing spiritual distress, it is important to raise this with their caregivers and offer support.

Responding to Spiritual Distress

Most hospitals have board-certified clinicians / chaplains who are part of the multidisciplinary team and who work with children and families regardless of their particular faith practice or lack thereof. These clinicians are trained to be present and compassionate with each person during the scariest and most threatening of times. Caregivers may also want to connect with their own spiritual advisor (e.g., rabbi, priest, minister, imam).

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While making a referral is often the first action to be taken, it's also important to have strategies for responding in the moment to statements of spiritual concerns from children or caregivers. Consider these interventions:

- Listen deeply, without an intent to fix, as some spiritual concerns just need to be stated / heard, and resolution may not be possible
- Validate the individual's feelings
- Ask what types of supports have helped during other difficult times
- If appropriate, invite the child (and family members if present) to express their feelings through play or art

Attending to Clinician Spirituality

Clinicians also may benefit from being aware of and nurturing their own spirituality. Questions to consider:

- Do you have practices or rituals that sustain you?
- Where do you turn when feeling depleted or that you cannot hold any more pain and sorrow?
- Do your ideas change as you care for seriously ill children? If so, how?

Self-reflection and attention to self-compassion practices will benefit the holistic care you are able to provide to families.

Note: If you train other clinicians, you may wish to be alert for symptoms of their spiritual distress and, if appropriate or necessary, refer them to appropriate supports.



Conclusion

Acknowledging the whole-person paradigm—physical, emotional, social and spiritual—in clinical care can lead to deeper relationships. Patients and caregivers appreciate and want clinicians to inquire about their spiritual practice and to be respectful of their ways of coping, easing fears and maintaining hope. Responding to and validating their needs can help to build confidence and trust.

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Resources for Clinicians



Videos



“I believe in the power of positive thought.”

Parents reflect on the role of faith and positive thought in their life. <https://courageousparentsnetwork.org/videos/i-believe-in-the-power-of-positive-thought/>



“Chaplain: Spirituality is how we make meaning.”

Hospital chaplain discusses the many ways in which people make meaning. <https://courageousparentsnetwork.org/videos/chaplain-spirituality-is-how-we-make-meaning/>



“For many people it’s a huge crisis of faith.”

Pediatric psychologist and a father discuss the role of faith in the family’s lived experience of serious illness. <https://courageousparentsnetwork.org/videos/for-many-people-its-a-huge-crisis-of-faith/>

Resources for Families



Unit

Courageous Parents Network Unit “Spirituality”

Videos, downloadable guides and other information designed to help patient families. <https://courageousparentsnetwork.org/topics/spirituality-2>