Spiritual Care: Providing to Children and their Families

What Is Providing Spiritual Care to Children and Their Families?

Spiritual care is the provision of interventions that address clients’ and families’ spiritual needs. Spirituality is recognized as a vital component of emotional and physical health. Spiritual care is important to the achievement of an overall sense of well-being because spirituality can have an influence on the behaviors and beliefs of a client and his or her family.

What: Spirituality is a highly individualized concept that has been variously defined as one of the core values of an individual’s life; belief systems that sustain the individual through times of distress; or an individual’s conception of the meaning of life, which forms the core of his or her relationship with others and/or God (as defined by the individual). An inclusive definition proposed for social work practice describes spirituality as a “subjective relationship (cognitive, emotional, and intuitive) to what is unknowable about existence, and how a person integrates that relationship into a perspective about the universe, the world, others, self, moral values, and one’s sense of meaning” (Senreich, 2013, p. 553). Faith is thought to be the foundation of spirituality and is a belief in something that one cannot see with physical sight. Religion is a systematic approach to spirituality that has a set structure, standards, or dogma that can offer a person spiritual support while providing moral uplifting and outlining moral standards of behavior (Kilpatrick et al., 2009). Spirituality, faith, and religion are distinct concepts that have different meanings for different persons. For some persons, spirituality is synonymous with and experienced through participation in organized religion, whereas for others spirituality is explicitly distinguished from religion. Spiritual care is designed to support spiritual beliefs and alleviate symptoms of spiritual distress, which can occur when a person’s ability to experience and integrate meaning and purpose in life is diminished. Since 1994, the Council on Social Work Education has required that all master’s degree programs in social work include education and practice content on working with clients from a variety of religious and spiritual backgrounds. Clinicians should be aware that the elements of spiritual, pastoral, and culturally competent care often overlap.

How: When providing spiritual care to children and their families, social workers will conduct a spiritual assessment, determine if the client and family have any specific spiritual and cultural needs and strive to meet those needs, provide active listening to the client and family, and promote an environment that is conducive to family bonding.

Where: Spiritual care can be provided in any social work setting, including pediatric units and pediatric intensive care units (PICUs) in hospitals.
Who: Social workers are a key component of the multidisciplinary team in any healthcare setting and often are utilized in difficult situations with young clients to help the client and family with physical, social, emotional, and spiritual needs. This makes them one of the main providers of spiritual care to the pediatric client and his or her family.

What Is the Desired Outcome of Providing Spiritual Care to Children and Their Families?

The desired outcome of providing spiritual care to children and their families is spiritual health, improved emotional and physiologic outcomes, decreased levels of stress and emotional turmoil related to being sick near the end of life or having a child who is sick or dying, and an overall improved sense of well-being for both children and families.

Why Is Providing Spiritual Care to Children and Their Families Important?

Spirituality can play a significant role in the lives of children and their families, shaping their beliefs about meaning and purpose, how they perceive and cope with adversity, their decisions about treatment, and the internal and external resources they are able to access.

Childhood illness and/or end-of-life medical situations often are difficult to accept. Children with chronic and/or life-threatening illnesses, as well as families of sick children, frequently question their spiritual beliefs. This can lead to spiritual distress, with symptoms of anger, sadness, anxiety, uncertainty, fear, confusion, hopelessness, meaninglessness, and despair. Spiritual care can alleviate these symptoms through support of the child and family.

Pediatric clients should have their own spiritual needs assessment to identify what spiritual beliefs they hold, determine sources of strength or fears, and determine what relationships are important to the clients.

Facts and Figures

- The Pew Research Center reported that in 2015, approximately 84% of persons worldwide were affiliated with an organized religion. Of the global population, the three largest religious groups are Christians (31%), Muslims (24%), and Hindus (15%). Approximately 16% of the world’s population do not belong to a religious group, although many of these unaffiliated individuals report having some type of spiritual or religious beliefs (Pew Research Center, 2017).
- In a 2016 Gallup poll, 89% of Americans surveyed said they believed in God, 53% stated that religion was very important to them, and 22% stated that it was fairly important (Gallup, 2016).
- Many childhood deaths are unexpected, but approximately 15,000 children die each year from illnesses for which palliative care (i.e., comprehensive care administered to clients with severe and/or terminal illness) is appropriate (Gerhardt et al., 2009).
- 95% of children with cancer between the ages of 8 and 17 wanted to be told if they were dying (Gerhardt et al., 2009).
- In a pediatric palliative care setting in the United States, the majority (88%) of children’s caregivers indicated that spirituality/religion was important to them, and 67% reported that they would like for medical staff to assess their spiritual/religious needs. Caregivers expressed feeling more supported when their spiritual/religious needs were assessed; none indicated being uncomfortable with professionals inquiring regarding their spiritual/religious needs (Kelly et al., 2016).
- Respondents in focus groups in nine countries (Belgium, Canada, Finland, Kenya, Poland, South Africa, South Korea, the United Kingdom and the United States) expressed similar spiritual concerns and emphasized the importance of healthcare professionals initiating discussions about spiritual care with sensitivity, providing a safe space for them to express spiritual concerns, and educating them about spiritual care. Participants reported that spiritual care was often lacking in healthcare settings, in part due to staff not prioritizing spiritual care, and identified that skills of human connectedness (e.g., empathy, compassion) should be a priority for research and training (Selman et al., 2018).
- In a survey of neonatal intensive care unit (NICU) staff, researchers found that professionals who self-identified as Christian, Black and/or Asian reported the highest levels of personal spirituality and spiritual care in their work (Coughlin et al., 2017).
- Spiritual care is an important component of palliative care. The palliative model of care historically has been applied to older adults, but experts recognize that there is a great need for palliative care programs in pediatrics. Pediatric healthcare providers report feeling inadequately trained in end-of-life care, and some feel personal discomfort in handling end-of-life care for children.

What You Need to Know Before Providing Spiritual Care to Children and Their Families

Social workers should understand the concepts of spirituality, religion, spiritual distress, and spiritual care.

- Spirituality is highly individualized and is defined by families in a variety of ways.
Religion is a system of faith and worship involving shared beliefs and traditions; religious affiliation is only one aspect of an individual’s spirituality.

Spiritual distress can reflect both spiritual and religious concerns.

Spiritual care involves conducting a spiritual assessment; developing an accurate understanding of the client’s spiritual concerns; and responding appropriately to the client’s spiritual needs.

Social workers need to understand the differences between spiritual care, pastoral care, and religious rituals.

The social worker needs to know what care he or she can provide and when he or she needs to refer to a chaplain or other religious figure to provide additional comfort and care.

Children in early and middle childhood usually follow their parents’ spiritual/religious lead and often conform to the expectations of their family’s religious or spiritual practices.

Rituals and beliefs might be a source of comfort to these children.

Adolescents are developmentally primed to question and often rebel against their family’s spiritual/religious beliefs and explore other perspectives. This can create challenges if adolescents are unable to access previously held spiritual beliefs and practices or hold beliefs that are different from their parents’ beliefs. Social workers should explore adolescents’ spiritual beliefs and practices, as well as eliciting information from parents regarding the family’s spiritual beliefs and practices.

Despair, ambivalence, discouragement, anger, resentment, detachment, isolation, hopelessness, and fear are feelings that may be present when a pediatric client or family member is in spiritual distress.

The client or family member may express anger toward God, regret or blame about the illness, need for forgiveness, and questions about the meaning of life, death, and suffering along with feelings of emptiness.

Symptoms of spiritual distress may manifest in the client or family member as displacement of anger, fear, etc. by lashing out at medical staff or the social worker.

Knowledge of why providing spiritual care to children and their families is important.

Families of children with life-threatening conditions or illnesses may have their spiritual distress compounded by their pursuit of a curative course that causes physical pain and suffering.

Minor children do not decide for themselves whether to stop treatment or pursue palliative care. The burden of these decisions is placed on parents and guardians.

Spiritual beliefs influence families’ decision-making regarding medical care.

Families value their rapport with healthcare providers and their ability to trust the information they receive from clinicians.

Maintaining open communication with clients and families can have a positive effect on their spiritual health.

Healthcare providers can encourage realistic hope specific to the family’s needs with regard to information, expectations, and values and preferences related to end-of-life care.

Social workers should provide the parents with a space and time to have their story heard so they can share their experience. The ability to respectfully understand and care for the spiritual needs of individuals with different belief systems or religious faiths is essential.

Convey openness and respect with regard to different spiritual or religious practices or beliefs.

Do not prescribe particular spiritual or religious practices or beliefs.

Remain nonjudgmental.

Do not impose a specific religious or spiritual frame of reference.

Be aware that with older children there may be a conflict between the values of the client and those of the family.

Be sensitive to personal biases. The social worker’s spirituality can be an asset but also an obstacle to supporting the client and family. Do not let personal values impose on the supportive process of providing spiritual care.

Treat clients and families with kindness, focused attention, and compassion.

Social Work Responsibilities With Regard to Providing Spiritual Care to Children and Their Families

Review the facility/unit/agency-specific protocol regarding spiritual care to children and their families, if available.

Facility protocol may prohibit visitation in designated areas by non-family members. Advise the family of facility policies that may affect visits by the family’s spiritual advisors. If non-family members are not allowed in the treatment area, find a suitable alternative place to meet.

Review the client’s chart or record to see if any other discipline has documented any spiritual/religious preferences.

Obtain a facility/unit/agency-approved spiritual assessment if available. If not available, prepare the appropriate questions to ask the client and/or family to perform a spiritual assessment.

Conduct a spiritual assessment of the client and family.
• At a minimum, the assessment needs to determine whether any spiritual practices are important to the client, and, if so, to ascertain beliefs and denomination
• Use language and approaches that are appropriate for the child’s age and developmental stage. Stories, drawings, and other strategies can be used to help the child to express his or her perceptions and beliefs
  – If there are elements of the spiritual assessment that are not appropriate to ask the child directly, direct the question to the parent or guardian
• FICA is an acronym for four questions to ask parents as part of a spiritual assessment:
  – Faith and belief: Do you think of yourself as spiritual or religious or both? What is your faith or belief system? What gives your life meaning?
  – Importance and influence: How important is faith in your life? Do your beliefs influence how you care for yourself and your child?
  – Community: Are you a member of a religious or spiritual community? Does this community provide support? If yes, how?
  – Address: How do you want me to address these issues in the healthcare plan for your child?
• The Joint Commission suggests 15 specific spiritual assessment questions, but the brief model above incorporates all of those questions
  › Observe for unspoken spiritual preferences
    • Note whether client or family members are reading religious materials, praying, watching or listening to religious programs, wearing or displaying religious symbols, or speaking of spiritual matters with others
  › Determine the risk for spiritual distress
    • Identify minor clients with a life-threatening illness or serious medical condition
    • Ask clients, parents, and guardians how they are coping with the illness
    • Ask if they are having feelings of sadness, anxiety, loneliness, or fear
    • Ask to whom clients and/or families are looking for spiritual support and whether support is available to them
  › Assist with spiritual expression, when requested
    • Help parents/guardians with making contact with their own religious leader if available, or with a facility-based or community-based religious leader of their faith
    • If they do not have a specific religion, make the appropriate referral to facility chaplain
    • Provide access to spiritual books, music, and videos
    • Provide quiet and privacy for prayer, reflection, and/or meditation
    • Become aware of any specific spiritual/cultural/religious days of observance and be respectful of their significance to the family
    • Provide a safe space for clients to express their questions, feelings, and concerns; shared activities or stories can facilitate spiritual expression in children, and adolescents may find writing activities (e.g., poetry, stories, journaling) helpful
  › Encourage families to spend meaningful time with clients
    • Facilitate time for frequent visitation
    • Provide quiet and solitude to allow families to spend time with their children without distraction
  › Facilitate communication with clients and families
    • Remain alert for an invitation to talk about their situation or any spiritual distress
      – Examples include “I wonder if I am making the right choices,” “What have other kids done?,” “What have other parents done?,” “Have you had other clients who have survived this?,” and “I think the doctor is not telling us everything”
    • Use nonjudgmental, open-ended questions to discover client and family wishes
      – Examples include “Can you tell me more about how you are feeling about…?,” “What can I answer for you?,” “What is your biggest fear at this moment?,” “What is most important to you and your child right now?”
  › Work to help pediatric clients strengthen relationships and connections with others
  › Enable and support hope to decrease spiritual distress
    • Encourage the sharing of feelings while actively listening
    • Ensure that families receive accurate medical information
    • Support and encourage clients and families to have control over their circumstances, environment, and choices whenever possible to decrease feelings of helplessness and hopelessness
    • Assist clients and families in finding meaning in their situation
    • Help them have realistic goals
• Facilitate communication that is positive and effective within the family, especially if there are disagreements about treatment decisions
• Assist with developing spiritual support in the community or the home if they are not already present
• Refrain from disclosing personal religious or spiritual beliefs
  › Document in the medical records all spiritual care provided and update clients’ plans of care, including
    • time and date of spiritual assessment
    • spiritual needs expressed by the family
    • actions taken to provide spiritual support
    • the family’s response, positive or negative, to spiritual care

Other Interventions That May Be Necessary Before, During, or After Providing Spiritual Care to Children and Their Families
  › When appropriate, request referral to the facility-based chaplain for further assistance with spiritual distress
  › Changes in a child’s physical health or prognosis can create anxiety and spiritual distress for the family. Remain alert for indications that the family would benefit from reassessment
  › If a client’s prognosis changes to a terminal prognosis, assist the family in locating appropriate resources
    • Be familiar with local and national grief resources that are specific to loss of a child and sibling loss and provide this information to family

What Social Work Models Are Used with Providing Spiritual Care to Children and Their Families?
  › Spiritual ecomap
    • This is a pictorial tool that depicts the client’s or family’s spirituality in terms of rituals, God/transcendent being, religious community, spiritual leadership, parents’ spiritual tradition, and transpersonal beings (e.g., angels, deceased loved ones). The ecomap shows how the client’s or family member’s spirituality has been influenced by previous generations, evolved over the client’s or family member’s lifetime, and is presently being influenced
  › Spiritual life map
    • This is a pictorial tool in which the client or family member constructs a time line of spiritually significant events and/or experiences using words, drawings, and/or pictures. The process of constructing the life map helps to facilitate memories, self-reflection, dialogue, and greater coherence of one’s life narrative
  › Generalist practice
    • Supportive presence
    • Therapeutic touch
    • Effective communication
    • Emotional connection
    • Creating a supportive environment
    • Referral to a formal spiritual caregiver
  › Cognitive behavioral therapy
    • Centers on assisting clients and families in identifying negative thoughts and helping them substitute more functional self-statements

Red Flags
  › Families of children with a terminal illness are at increased risk for impaired coping ability and a complicated grieving period. Spiritual care should be provided to these families as part of a multidisciplinary palliative care program that includes bereavement support
  › There is a high risk of divorce in families that have experienced the loss of a child. Be aware of marital tensions with parents and assist where appropriate
  › Any staff members working with children with terminal illnesses can be at risk for caregiver fatigue and secondary traumatization. Social workers need to monitor staff members and provide support and/or opportunities for them to receive spiritual care, and take part in services or programs on the unit to help relieve caregiver fatigue and process their own grief
  › The child’s developmental stage needs to be considered during any assessment; assessment tools should be developmentally appropriate and understood by pediatric clients
What Do I Need to Teach Clients’ Families?

- Educate family members on how to address the spiritual needs/distress of siblings of the sick child
- Siblings can feel left out and resentful, which may lead to feelings of guilt

References


Medicine, 21(9), 430-438.


