

Part A: Understanding Grief and Loss in Children and Their Families

Discussion Guide: Spiritual Humility at the Time of Illness and Dying

Learning Objectives for this Module

- Understand how a person's beliefs, culture, and spirituality, as well as background and experiences, might affect their response to communication of sensitive information.
- Describe physician approaches to spiritual issues that families believe to be helpful when faced with life-limiting illness or death of a child.
- Demonstrate understanding of the specifics of different cultural or spiritual beliefs that may impact families and assist in their integration of the experience.
- Know how to incorporate a chaplain as an essential member of the health care team.

Relevant Milestones: PROF1, PROF3, ICS1, ICS2

Introduction

Spiritual beliefs may serve as a comfort and unifying concept for a patient and family at times of disclosure of a new medical diagnosis, ongoing illness, or death of their child. Research indicates that 90% of the US population practices spiritual or religious traditions. In order to support families through their difficult journeys, clinicians need to try to understand and respect these beliefs. **Every attempt should be made to either implement important family traditions, or explain why they cannot be done in the health care setting and design alternatives that meet the family's needs.**

This module reviews the importance of acknowledging the spirituality of patients and families, and finding ways to elicit that information from them. We provide a brief overview of six of the world's major religions and traditional practices that may be relevant during illness or at the time of a patient's death. Finally, the importance of involving a chaplain as an integral member of the health care team is reviewed.

Understanding the Family's Perspective

Families request integration of their spiritual beliefs into the medical care of their children. In a study by Robinson et al (Robinson), four explicit spiritual themes have been found to be critical at end of life: **prayer, faith, access and support of clergy, and belief in the endurance of the parent-child relationship beyond death.**

While understanding religious traditions is important, not everyone linked to a religious tradition believes or practices all of its teachings. It is important to understand individual interpretations. Moreover, children's beliefs may differ from those of their parents, or two parents may have different beliefs. Hence it is critical to not make assumptions that all hold the same beliefs and inquire about individual differences and interpretations. When the patient and/or the parents differ in their beliefs, try to include representatives from both traditions to provide support. Parents have stated that they rely on spirituality to make meaning of health care experiences, yet 60-80% of parents with hospitalized children have felt they had unmet spiritual needs (Feudtner). Health care providers can provide critical resources to families. A health care provider can serve as a spiritual *generalist*, and know to inquire about the importance of spirituality in the patient's care. They can then offer access to clergy or spiritual specialists who can guide the family and provide specific, individualized support. Health care facilities can offer families access to multi-denominational chapels and services as a location for prayer and reflection.

Perspectives of Health Care Professionals

Understanding your own perspectives and beliefs about religion and spirituality is important to you as a health care provider. Inquiring and respecting another's spiritual belief is not being unfaithful to one's own beliefs. Rather, health care professionals need to be secure enough in their own beliefs to allow others to follow theirs. Health care providers should be receptive to the beliefs of patients and families and not try to force their beliefs on others. The skills of effective listening and mutual respect are critical. Since no individual can possibly know about all the world's religious traditions, ***spiritual humility allows us to acknowledge what we don't know, but remain committed to asking questions to better understand.***

Taking a Spiritual History

Including the spiritual dimension in a dialogue about sustaining life gives the family a segue into accessing resources that are a critical element of comprehensive care such as receiving support from a spiritual community, or incorporating spiritual practices into the hospital setting.

Spirituality refers to the relationship of an individual or group with the transcendent and is tied to the search for life's meaning. For some, spirituality may be experienced or expressed through religious practice; for others, relationships to nature may more accurately reflect their spiritual connections.

There is an extensive literature on taking a spiritual history. The point is to be very general in your inquiry so families feel more comfortable sharing their connection to the meaning and purpose of life, how they find meaning in suffering, what they believe about the possibility or faith in an after-life, and their spiritual practices that enhance feelings of connection with God/the Creator.

One of the biggest challenges we face as health care providers is not taking anything for granted. For example, a parent may have grown up as a Catholic but now turns to Buddhist meditation as an expression of connection to the divine one. With inter-cultural and inter-faith marriages becoming more common, there may be surprises in how faith is practiced and which restrictions/social and religious codes are adopted and which are not. Thus, when we first meet a family, we may not know by their outward appearance, or even their social history what their actual spiritual beliefs are until we create space for them to be shared.

Consider opening the discussion with this question:

"What role does spirituality or religion play in your and your child's life?"

(Sulmasy)

We provide two models of different frameworks in taking a spiritual history. The first model uses the pneumonic FICA and was developed by Astrow et al 2001, Post, Puchalski and Larson 2000. The second uses the pneumonic SPIRIT and was developed by Maugans. Both can be utilized in taking a spiritual history from a patient or family of a child with a potentially terminal illness.

FICA (Astrow, Post, Puchalski and Larson)

- 1. Faith and beliefs:** Is there a particular faith(s) that you and your family are members of? Are there any beliefs important to you that you would like to share?
- 2. Importance:** How would you rank the importance that spirituality plays in your life? (Very important/ Important/ Not very important)
- 3. Community:** Describe your connection, if any, to a spiritual community. How do you see this community supporting you in times of challenge?

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

4. **Addressed:** How can the healthcare team support your child and family in your faith and spirituality at this time? Are there any issues about this that you would like addressed?

SPIRIT (Maugans)

1. **Spiritual belief system:** Do you have a particular faith or sense of spirituality that is a part of your life?
2. **Personal spirituality:** How do you personally express your spirituality/ connection to something greater than yourself?
3. **Integration with a spiritual community:** Is there a spiritual/faith community you are a part of? Are there any regular religious or spiritual practices you are a part of through this community?
4. **Ritualized practices and restrictions:** Are there any restrictions or laws/ rituals that you follow as part of your faith?
5. **Implications for medical care:** Can you see a role for spirituality in what you are facing with your child now? Do you wish to incorporate a particular practice/ have a member of your community come in to provide a practice for your child?
6. **Terminal events planning:** In the event that someone dies, what are any rules or beliefs/rituals that should be carried out? Please share these with us.

The questions from these frameworks can help you to begin the dialogue of understanding a patient's spiritual beliefs and the ways in which patients and families may feel the need to be supported.

Families may ask several questions of themselves or health care providers when confronted with their child's life-altering diagnosis, chronic illness, or end of life issues and death. Some examples (adapted from Robinson, 2006) include:

- Why is this happening? Is my child's illness (death) a failure on my part as a parent to protect my child adequately?
- Is this a punishment for something that I have done?
- Is my child's illness (death) part of a bigger or divine plan?
- Is there some greater good in relation to which my child's death becomes acceptable? (organ donation, research options to help others)

While these questions may be difficult to hear, they provide insight into the parent or patient's perspective. Some of these questions may not have answers, but allowing families the opportunity to express them can lead to stronger relationships and also convey the message that you care about their spiritual beliefs. All medical providers should have insight into the importance of spirituality to families and develop competence in discussing this topic with them. They should be competent as *spiritual generalists*. Then, when more information is acquired, the medical providers can refer to clergy or to spiritual specialists, who may be able to provide more individualized counseling and support. Health care facilities assist families by having clergy on call and also allow families access to a multi-denominational chapel where families can pray or meditate. Specific spiritual healers can be invited to participate in the care of patients at the family's request.

Concept of spiritual humility

There are many religious traditions worldwide. No provider can know everything about all them, but the next section of this module will provide an overview of basic concepts from each of the six prevalent religious traditions. (Fossarelli)

Our goal is to teach medical providers the importance of spiritual humility about religious traditions. ***Spiritual humility allows us to acknowledge what we do not know, but seek to understand.*** Providers need to understand broad concepts, and be willing to inquire of families about specifics. They also need to understand that families may have individual beliefs or cultures, even within their religious tradition.

Overview of World Religions

Developing an understanding of some of the world's religions will help the provider to be sensitive to the needs of families in order to make special accommodations for spiritual or religious observance, and make an effort to incorporate religious traditions within the hospital setting when possible. Please realize that there may be great variability within a religious belief and the practices listed may not be practiced by all those who state their belief in the religion. The overviews presented are to encourage health care professionals to consider the spectrum of possibilities and also to clarify with the patient and family the spiritual beliefs and practices that are important to them. The reference by Dr. Fosarelli, *Prayers and Rituals at a Time of Illness and Dying*, 2008, has been used to summarize six of the world religions below. They are classified as Eastern religions which includes Hinduism, Buddhism and Sikhism while the Western religions include Judaism, Christianity and Muslim or Islamic beliefs.

Hinduism

Hindus believe in God as the Brahman. They believe that God is within and transcends every created being, so the essence of each soul is divine. To attain knowledge of one's "True Self" one must experience minimal fears about living and dying. This is accomplished by surrendering to God and offering everything one does as a sacrifice to Him. The results of deeds done in past lives are visited on in one's future life, which is the law of karma. Liberation from suffering occurs through spiritual knowledge. Hence, death entails reincarnation repeatedly until one finally achieves union with Brahman or one achieves a blissful state of liberation in paradise.

Some general concepts to consider regarding Hindu practices with ill patients or at the time of death include that the health care provider may want to discuss with the family how they want the information presented to the patient and in what detail. Oftentimes the father is the major decision maker with the patient's mother following his instructions. Specifics about death rituals should be consulted with the family and, as with any patient, the body is treated with the utmost respect. The timing of the funeral is often within 24 hours. The patient's body is often cremated, and, as noted above, many Hindus believe in reincarnation.

Buddhism

Buddha taught that suffering (termed dukkha) results from ignorance of how things really are (or dharma). Things are not permanent but are always changing. Suffering results from trying to hang on to the present, as if it will never change. Those of the Buddhist tradition believe that one is reborn, not reincarnated, because traditional Buddhism does not believe in a "True" (unchanging) Self as Hinduism does. Death results in rebirths until greed, hatred and delusion are eradicated. Compassion and wisdom are Buddhist moral values and lead to happiness. Buddhists do not believe in a personal God.

Some general concepts to consider include that meditation and rituals may be important at the time of death. Some believe it is important to die with a positive state of mind and to be at peace. Others may value death with clear consciousness, so the family or patient may demonstrate reluctance in using pain medication. For some, there may be the belief that the "person" remains with the body for 3 days, so cremation only occurs after 3 days.

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

Sikhism

In the Sikh belief, there is only one immortal God. All human beings are equal; therefore, harmony and non-violence are expected values. Basic principles and practices during life include meditation, work, charity and service to God and others. The five religious symbols of faith are worn by devout Sikhs and are called the five Ks or Kakkas's. These include: Kesh (uncut hair), Kangha (wooden comb), Kara (iron bracelet), Kirpan (short sword), and Kachera (undergarment).

These religious symbols of faith have the following meanings. Uncut hair is to maintain and adorn the natural God-given gift in the spirit of working with nature and not against it. The wooden comb is a reminder to regularly maintain the body and mind in a clean and healthy state. The iron bracelet serves as a reminder that the Sikh is a slave of the Lord and he or she must only do His work in accordance with the Holy Scripture. The short sword is a sign of a soldier who is ever ready to maintain and protect the weak and needy and for self- defense. The undergarment is worn as a comfortable, dignified attire that reflects modesty and control.

Those who practice Sikhism may prefer a health care provider of the same gender. Sikhs may consider their illness to be the will of God, but they also try to get well by adhering to medical advice. The sanctity of the human body is assumed; therefore, euthanasia is not endorsed, but needlessly prolonging a dying person's life is discouraged. After death, a soul is born into another body (either human or in an animal) but it is only through human life that one can find God. Sikhs are very strong in their belief of reincarnation. They believe that all humans and animals have a soul and respect all living beings.

Religious traditions should be respected and also family preferences for any rituals should be elicited. If the patient had carried the religious symbols of faith noted above, the family may prefer to have those symbols remain with the body, as the body still has the same dignity that it had in life. Cremation is a usual practice.

Judaism

There are 5 branches of Judaism: Hasidism, Orthodox, Conservative, Reconstructionist, and Reform. These branches span a wide variety of customs. Important themes within Judaism include creation, revelation and redemption. There is only one God, who made everything and who seeks to save human beings. It is imperative to follow God's commandments, especially to love God and other people. The ill person is often accompanied by family members when possible.

After a person's death, mourners may make a small tear in their clothes or wear a ribbon or ripped garment as a sign of their grief. This is a symbol that the deceased was torn away from the family. The body is not left alone until burial, which traditionally occurs within 24 hours or before sundown on the same day if possible. Specific guidelines for preparation of the body depends on the branch of Judaism. There may be variable opinion about autopsy, organ donation or cremation so this should be asked of families. Some families may not cremate the deceased as it may serve as a reminder of the Holocaust. The family will often sit Shivah, a practice in which they remain at home for up to one week after the death to observe the mourning process. This includes prayers and refraining from daily activities such as work, cooking and showering. The family will often receive visitors in their home.

Christianity

There are many branches within Christianity which includes a heterogeneous group of religious denominations; Roman Catholicism, Baptist, Lutheran, Anglican, Presbyterian and Eastern Orthodoxy. It is important to never assume a religious practice is the norm for all groups. The unifying beliefs for the above mentioned groups include belief in the Father, Son and Holy Spirit (trinitarian denominations) and belief in resurrection of the body and in an afterlife of either eternal happiness or eternal torment depending on whether one lived a good life. The most important commandments are to love God and to love others. While different branches may have different traditions, prayer for the ill person and his/her family is usually appreciated.

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

It is also important to remember that within Christianity there are also non-trinitarian denominations that include the following denominations: Latter Day Saints (Mormonism), Christian Scientists, Unitarian universalists, Jehovah's Witnesses, and Iglesia ni Cristo (Church of Christ).

For those whose belief is as a Jehovah's Witness, members may see death as a state of non-existence, a state of no consciousness. Two other important aspects are not believing in blood transfusions and conscientious objection to military service.

Those who practice as Christian Scientists often view disease as a mental health or emotional problem and the sick should be treated by prayer to correct the illusions of bad health. (Britton)

Specific traditions or rituals are dependent on the denomination. For some, the anointing of the sick and confession of sins may be important. Euthanasia is not endorsed by Catholics, Orthodox Christians and individuals of certain other Christian traditions, but most traditions believe that extraordinary means need not be initiated if death is imminent. All religious groups treat the body with respect after the death. Organ donation may be acceptable to some denominations but may not be acceptable to an individual family so this must be considered with religious guidance within the broader family context and culture. Some denominations endorse cremation, while all support burial in the ground.

Muslims and the Islamic Beliefs

The Muslims believe in Allah (God) who is the one God and creator of everything. Everything belongs to Allah and Allah wills all that happens in a person's life. The Prophet Muhammad received the Qur'an (the Muslim sacred text) from the angel Gabriel. Muslims advocate to withstand and learn from the trials and tribulations that may occur in their life as a test from Allah as to how one will deal with the challenge. There are five schools of Islamic thought and this is important to acknowledge since religious beliefs and practices may have important nuances. Various sects of Muslims have developed over centuries which have contributed to different funeral rites and customs drawing on various sources sacred to them in addition to cultural traditions. It is important to distinguish between what is accepted religiously within the confines of Islam and what is practiced culturally by the varied Muslim communities. There are cultural differences in the groups of Muslims in the United States who are African American (about 35-40%), Southeast Asian extraction (30%) and Arabic (15%). These cultural differences would influence specific views of viability and end of life. Hence, it is again important to emphasize the concept of spiritual humility and asking families to educate us as health care providers about the specific beliefs they hold and cultural practices they endorse.

The 5 pillars of Islam beliefs include:

1. Declaration of faith called the Shahada that professes that there is but one God and Prophet. Mohammad is His messenger.
2. Prayer facing Mecca 5 times each day.
3. Almsgiving of at least 2.5% of income.
4. Fasting during the month of Ramadan. (Those exempted from fasting may include people with acute or chronic illnesses, young children, and women who are menstruating, pregnant or breastfeeding).
5. Pilgrimage to Mecca at least once in a lifetime.

Religious traditions and rituals are often led by the Imam who is their spiritual leader. Some people invite a clergy member to say collective prayers for the patient on his/her behalf. Muslims may vary in their beliefs about cremation, autopsy or organ donation so it is important to ask. There are no prohibitions against making a will to donate one's organs after death in the Qur'an. It can be seen as a high form of charity similar to donating one's assets for the needy. Since many believe in resurrection, there may exist a preference that the body remains intact and this may influence the response to a request for autopsy. Sects that follow ahadith, strive to bury as soon as possible after the death.

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

Case: Impact of understanding and incorporating spiritual beliefs.

The scenario below is based on a real case where the family believed that their faith and beliefs had a tremendous impact on both their child's outcome and their own ability to find support during those times when their child was close to death.

You are a third-year pediatric resident on your neonatology rotation. You are assisting the fellow and attending in the care of an 18-hour-old infant transported from a nearby hospital for a right-sided diaphragmatic hernia discovered shortly after delivery. The infant is full term and intubated. The CT scan reveals a right hemispheric infarct thought to be due to poor oxygen saturation during resuscitation efforts in the delivery room. The fellow tells you that the only hope is to place the infant on ECMO once the attending confirms that decision the parents request full life support.

The attending informs the family that the infant has a 3% chance of survival based on previous outcomes of this diagnosis at this hospital. The mother is of Persian decent and the father is from Bolivia. They nod in silent acknowledgement and request full support for their son, Luke.

The attending activates the ECMO team and the neonatal surgical team. She asks you to take a spiritual history from the parents to set the stage for any practices/ beliefs that may be important to them as they make what are likely to be very difficult decisions regarding their son's care.

The family shares that they are both Baha'is, a faith that is unfamiliar to you. They believe in the existence of a soul that lives on after the body dies. The mother shares that the body is viewed as a cage and the soul is the bird. When the cage is broken, the bird flies and is unharmed. When asked what support you can offer them, they ask if they can hang a copy of the prayer that members of their community are saying for him over his bed.

The child is placed on ECMO and the team works to stabilize the infant. A gortex graft is sewn into the diaphragm while gradually putting traction on the liver and intestines to pull them into the abdominal cavity. The attending shares with the family that Luke remains in critical condition and encourages them to lean on their faith for strength. The child's 9-year-old sister and 11-year-old brother become closely involved, visiting regularly. The mother shares on rounds one day that the family believes that if they are strong as a family, it will help their son's chance of survival. The mother asks if it is okay when they visit to touch the baby despite all the lines and tubes. They are told to touch him where they could. When asked to leave, members of the family stood by the wall right outside his bed and prayed.

After two weeks, the attending physician shares with the family that despite having tried many different options, they are not able to definitively stabilize Luke and they believe disconnecting from ECMO in the next 24 hours is in the infant's best interest. Because the infarct he suffered at birth was massive, there is no guarantee that Luke would be able to breathe or maintain his blood pressure when the ECMO is withdrawn. The attending shared that some parents would opt to not institute further respiratory or cardiac support at this point. She said she had to tell them about this option out of duty, but she understood that, the way she had seen the family believe and love, they might not want to do that. The parents nodded in agreement and asked how they could help. The team told them to continue to be strong as a family and to do whatever practices from their faith they believed would sustain them and the baby through this difficult time.

The parents said they would be asking their whole community to pray for Luke that night and that they would like to camp near Luke's bed, but out of the way of the team, to be present for their son.

That night the mother and father sat in chairs at a distance watching as the team weaned Luke from ECMO, finishing at 7 o'clock the next morning. They constantly prayed. The nine people that made up the Local Spiritual Assembly, their administrative body, had come to the waiting room and they had all prayed silently as well.

To everyone's surprise, Luke survived the wean off ECMO. The family put a picture of Luke Skywalker over his bed, which remained with him over the next 2-month hospital stay. From then on, when the mom called, she would say this is Mama Skywalker, and would ask how Luke Skywalker was doing. She said she felt she was mixing her spiritual beliefs with a little magic.

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

The patient was weaned off oxygen and discharged after 2 1/2 months in the NICU, with a feeding tube. He went on to live for 16 years, with surgical repairs at 9 months and 2 1/2 years. Each time, the attending would say: Whatever it is that you are doing as a family (she knew the family prayed a lot for his health) please keep on doing it because it is working. The mother shared that the bond of closeness that was built led her to stay in touch with his surgical nurse and neonatal physician throughout the course of Luke's life.

When asked for a belief that she wished to share which impacted her decision-making in the ICU, the mother shared the following quote that she said has brought her joy and appreciation for her son's survival from impending death on more than one occasion:

"As to those souls who are born into this life as ethereal and radiant entities and yet, on account of their handicaps and trials are deprived of great and real advantages, and leave the world without having lived to the full - certainly this is a cause for grieving. This is the reason why the universal Manifestations of God unveil Their countenances to man, and endure every calamity and sore affliction, and lay down Their lives as a ransom; it is to make these very people, the ready ones, the ones who have capacity, to become dawning points of light, and to bestow upon them the life that fadeth never."

'Abdu'l-Baha

The family picked up this theme—dawning points of light—in a ceremony they had for Luke after he died at age 16 from a heart attack related to his pulmonary hypertension. The mother shared that with her Faith she was able to accept his new life as a part of his continued development, considering this date his birth into the Spiritual world and accepted this as a cause for celebration in the same way that a baby's birth is a big celebration. It was at the second year anniversary that they had a Festival of Lights designed by her daughter for Luke where they hung strings of light in the house and friends could cut out flowers from colored paper and could write the name of someone in the next world to pray for and hang it on the chain of lights. They invited staff from the hospital to both his funeral and the Festival of Lights.

Here is a copy of a prayer for healing the family often said for Luke, both during that fateful night of weaning off ECMO and throughout his life:

"Thy name is my healing, O my God, and remembrance of Thee is my remedy. Nearness to Thee is my hope, and love for Thee is my companion. Thy mercy to me is my healing and my succor in both this world and the world to come.

Thou, verily, art the All-Bountiful, the All-Knowing, the All-Wise."

-Baha'u'llah

We hope this example demonstrates the importance and power of spirituality to families and that incorporation into their care can lead to both comfort to the families/patient and also the development of closer relationships between health care providers and family.

The Role of the Chaplain

As mentioned earlier, as the health care provider serves as a spiritual generalist, he/she may want to access a spiritual specialist when this is desired by the patient and family. The hospital chaplain will assist in this role. The hospital chaplain is trained to provide spiritual support to patients of all ages and to their families, with sensitivity and respect for their religious tradition (including those who are "spiritual not religious" and those with no affiliation). The chaplain will make a spiritual assessment and develop a plan of care based on the stated needs of the patient and family and in accordance with their religious and cultural values.

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

Providers do not need the permission of the patient or family to request chaplaincy support. There have been times when a provider asks directly and the chaplain's help is declined, but later the chaplain proves to be a helpful resource for the patient and/or family. For some, "chaplain" is associated with a particular religious agenda or with "bad news" or death itself.

Chaplains can provide spiritual support through a variety of interventions including:

- spiritual and emotional support through compassionate, empathic listening and a "ministry of presence";
- exploring questions of meaning and faith in relationship to illness and suffering (with patients and parents);
- use of prayers, sacred texts and rituals from the patient's and family's tradition;
- spiritual guidance with difficult medical decisions, including end-of-life care;
- support to the patient's and family's own clergy and members of their faith community;
- communication with members of the interdisciplinary team about spiritual aspects of the patient's and family's coping, including when there are differences with standard treatments or goals of care based on religious or cultural beliefs.

Most hospital chaplains are trained through an accredited program of Clinical Pastoral Education (CPE). To become a board certified chaplain, four educational units of CPE (1600 hours of supervised training in a clinical context) are required, along with a formal degree in theology or religious studies and the endorsement of one's faith community to serve in this role. CPE is an accredited program of training that places seminarians and ministers in a clinical context to learn how to provide effective pastoral and spiritual care based on the needs of the patient and family. Some faith groups require at least one unit of CPE to be an ordained clergy person.

Chaplains often attend interdisciplinary team meetings and there are times when including a chaplain in patient and family meetings can be helpful, particularly when there are spiritual beliefs that are important to their overall care. A chaplain can be an important liaison with members of the patient's own clergy or faith community, who may not have much experience dealing with acute pediatric and life-threatening illness.

Chaplains offer formal and informal education for staff in issues related to healthcare and spirituality, including how spiritual beliefs and practices foster coping and affect decision making. Chaplains also provide invaluable support to staff as they deal with the stress of caring for patients and families with complex and life-threatening conditions.

One of the best ways to learn about the role and function of chaplaincy is to shadow a chaplain and directly observe how a chaplain makes appropriate interventions and develops a plan of care based on a spiritual assessment of the patient/family. Residents, fellows and medical students are encouraged to make this part of their training. The bibliography at the end of this section includes helpful resources to learn more about how to address spiritual issues as part of one's medical practice and to work with chaplains and clergy to support the patient's spiritual coping.

Cases: Spiritual Humility

Case 1:

Your patient is a 6yo Middle-Eastern American boy whose family's faith is important to them. The child is dying from a progressive neurological disease for which there is no treatment. The family hasn't felt comfortable with their child dying in their home, so they request that their child be admitted to the hospital. However they want their spiritual leader to perform the death rituals in the hospital. How would you approach this request?

Points to consider:

1. What discussion would you want to have with the family?
2. What information would be important to know?
3. What resources could you access to assist with their request?
4. How would you navigate this request with the different disciplines involved with the child's care- parents, nursing staff, child life, and chaplain?

Case 2:

Your patient is a 17yo African American female Christian whose family's faith is vital to their daily life. She was admitted in acute respiratory distress and was intubated emergently. Her family has rejected the medical team's recommendation to discontinue aggressive treatment for her leukemia after a failed bone marrow transplant. They report that they are relying on God to intervene with a miracle and ask you to continue to do everything. Your patient has requested that no further treatment be initiated.

Points to consider:

1. What are your thoughts about this case?
2. What additional insights into the family's religious beliefs may be helpful?
3. What other team members may be helpful to assist with the care and decision making of this patient and family?

Case 3

A 7 day old infant is readmitted to the hospital for cyanotic episodes with feeding. The infant is found by echocardiogram to have truncus arteriosus and will require cardiothoracic surgery. The parents of the child disclose that they are Jehovah's witnesses and do not endorse blood transfusion.

Points to consider:

1. How would you approach the issue with the parents?
2. What discussions would you want to have with the cardiothoracic surgeon?
3. How do you balance the rights of the parents with the rights of the infant?
4. What additional resources might be of help to you?

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

Case 4

A 3 month old is brought into the PED pulseless and not breathing during the middle of the night. After 40 minutes of aggressive resuscitation without restoration of spontaneous breathing or a heart rate, the parents ask you to baptize their infant prior to stopping the resuscitation.

Points to consider:

1. What might be your reaction to their request?
2. How might your religious background/beliefs influence your approach?

The infant is declared dead at the end of the attempted resuscitation. The family is distraught and asks you to pray with them.

Points to consider:

1. What might be your reaction to their request?
2. Would it matter what your religious background/beliefs are?
3. Any guiding principles that would be important to you?
4. What additional factors might influence your decision?

Case 5

A 9 year old has been in the PICU following a major motor vehicle accident 6 days ago. The child has been found to have no brain activity on 2 separate EEG tracings. The family has agreed to discontinuation of life support and you are preparing the family.

Points to consider:

1. What questions might you ask them to understand their spiritual or religious beliefs?
2. What other team members would you involve?

Case 6

You have served as the primary care provider for a 4 year old since birth. The child died this morning from complications from a genetic disorder. The family asks you to attend the funeral of their child.

Points to consider:

1. What is your initial response?
2. Would it matter what your religious/background/beliefs are?
3. Would it matter what religious tradition they practice?
4. What additional information might you want?
5. What are ways in which you might prepare for the experience?

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

Case 7:

You are working in the PICU and a child is declared dead after a motor vehicle accident resulting in severe head trauma. The mother is distraught and states that in their Judaian religious beliefs, a family member must remain with her child's body until taken to the funeral home.

Points to consider:

1. How might you approach this request?
2. What would be your reaction?
3. What resources would you want to access within the hospital setting to try to honor this request?

Summary

Acknowledgement of spiritual humility by all health care providers is critical. One should always determine whether spiritual beliefs are important to a patient and family and then learn more about their individual beliefs.

The family should be asked about religious traditions and rituals in addition to cultural beliefs and providers should honor them within the hospital setting if at all possible.

Endorsement and support of a patient and family's spiritual beliefs can be accomplished while still being faithful to one's own beliefs. Remember, not all members of a specific religious tradition hold the same beliefs so respectful inquiry is essential.

Offering to include a chaplain as a member of the health care team should be routine. One can then defer to the family's wishes as to whether they would find his/her presence helpful and supportive.

Discussions of autopsy and organ donation must be individualized to the family and considered with religious guidance within the broader family context and culture.

Strive to determine the family's wishes regarding spiritual rituals at the end of life. Clarify issues such as family presence with the body and timing of rituals and/or funerals since these practices have implications for the timing of an autopsy specifically if a medical examiner is to conduct the post mortem examination.