Resilience in the Face of Grief and Loss:  
A Curriculum for Pediatric Learners

Part A: Section A.9

Spiritual Humility at the Time of Illness and Dying
Objectives

- 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.
Objectives (continued)

- 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.
Spiritual beliefs may serve as a comfort and help ground a family in their grief at times of illness and death.

90% of the US population practices spiritual or religious traditions. (Robinson 2006)

Clinicians should support and respect these beliefs.

Every attempt should be made to implement traditions that are essential or explain why they cannot be done in health care setting.
It is important to understand the individual spiritual beliefs of patients and their families, because not everyone in a spiritual tradition believes all the teachings.

Parents and children may have different beliefs as well, so inquire and not make assumptions.

Include clergy from the family’s tradition(s) as early in the illness as possible.
Understanding the Family’s Perspective

- Parents state they may rely on their spiritual beliefs to understand the meaning of their child’s health care experience and accept difficult news.

- 60-80% of families had unmet spiritual needs (Feudtner 2003)

- Four explicit themes are critical (Robinson 2006)
  - Prayer
  - Faith
  - Access to and support of clergy
  - Belief in the endurance of parent-child relationship beyond death
Resources to Provide Families

- Health care providers need to embrace spiritual humility, as no one can understand all the religious or spiritual traditions in the world.
- Medical provider as spiritual generalist – insightful about need for spirituality.
- Access to clergy or spiritual specialists who can help guide and support families.
- Access to multi-denominational chapel and services for place to pray and reflect.
Perspective of Health Care Professionals

- Inquiring and respecting another’s spiritual belief is not being unfaithful to one’s own beliefs. Rather, it is being secure enough in one’s own beliefs to allow others to follow their beliefs.

- We cannot possibly know all there is about another individual’s beliefs.

- Spiritual humility allows us to acknowledge that we don’t know, but seek to understand.
Taking a Spiritual History

- Allows families a segue into accessing resources that are a critical element of care.
- Receipt of support from spiritual community.
- Incorporate spiritual practices into the hospital setting.
- Need to not make assumptions. Don’t assume the two parents or the parent and child may have the same spiritual beliefs.
Open the Discussion

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

(Sulmasy 2002)
Taking a Spiritual History: FICA

- **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?

- **Importance:** How would you rank the importance that spirituality plays in your life (Very important/Important/Not very important)?

(Astrow 2001)

(Puchalski, Larson, Post 2000)
FICA (continued)

- **Community**: Describe your connection, if any, to a spiritual community. How do you see this community supporting you in times of challenge?

- **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?

(Astrow 2001)
(Puchalski, Larson, Post 2000)
Taking a Spiritual History: SPIRIT

- **Spiritual belief system:** Do you have a particular faith or sense of spirituality that is a part of your life?

- **Personal spirituality:** How do you personally express your spirituality/connection to something greater than yourself?

- **Integration with a spiritual community:** Is there a spiritual community you are a part of? Are there any regular religious or spiritual practices you are a part of through this community?
Taking a Spiritual History:
SPIRIT  (continued)

- **Ritualized practices and restrictions:** Are there any restrictions or laws/rituals that you follow as part of your faith?

- **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?

- **Terminal events planning:** In the event that someone dies, what are any rules or beliefs/rituals that should be carried out? Please share with us.  (Maugans 1996)
Families Often Ask:
Implicit Spiritual Themes

- “Why is this happening? Is my child’s illness (death) a failure on the part of me as a parent to protect my child adequately?”
- “Is my child’s illness a punishment for something 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 more acceptable?” (organ donation, research options to help others)

(Robinson 2006)
Concept of Spiritual Humility

- It is impossible for any health care provider to know all there is about different religions or spiritual beliefs.
- Begin as a spiritual **generalist**, and as you obtain more information you can refer to a spiritual **specialist** individualized to the family's needs.
- Spiritual leaders can be invited to participate in the patient's care.
Overview of World Religions

- Eastern Religions
  - Hinduism
  - Buddhism
  - Sikhism

- Western Religions
  - Judaism
  - Christianity
  - Muslim and Islamic beliefs

(Fosarelli 2008)
Eastern Religions

- Hinduism
- Buddhism
- Sikhism
Hinduism

- Hindus believe in God (Brahman).
- Hindus believe God is within and transcends every created being.
- Essence of each soul is divine.
- To attain knowledge of one’s “True Self,” one must have minimal fears about living and dying. This is accomplished by surrendering entirely to God, offering everything one does as a sacrifice to Him.
Hinduism (continued)

- Results of deeds done in past life are visited on one’s future life (i.e., law of karma).
- Liberation from suffering occurs only through spiritual knowledge.
- Death entails reincarnation repeatedly (according to karma), until one finally achieves union with Brahman, or one achieves a blissful state of liberation in paradise.
General Concepts to Consider in Hindu Beliefs

- Determine how family wants information presented to the patient and amount of detail.
- The father is often the major decision maker with the patient's mother following his instructions.
- Family members should be asked about specifics for death rituals.
- The timing of the funeral is often within 24 hours.
- The patient's body is often cremated.
- Many Hindus believe in reincarnation.
Buddhism

- Buddha taught that suffering (dukkha) results from ignorance of how things really are (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.

- Belief that one is reborn, not reincarnated, because traditional Buddhism does not believe in a “True (unchanging) Self” as Hinduism does.
Buddhism (continued)

- Death results in rebirths until greed, hatred, and delusion are eradicated, i.e. when a person becomes enlightened about the true nature of reality.
- Compassion and wisdom are Buddhist moral values and lead to happiness.
- Buddhists do not believe in a personal God.
General Concepts to Consider in Buddhist Beliefs

- Meditation and rituals may be important at time of death.
- Some believe it is important to die with a positive state of mind and be at peace.
- There may be a value placed on death experienced with a clear consciousness; hence a patient may be reluctant to take pain medications.
- For some, there may be the belief that the "person" remains with the body for 3 days, so cremation only occurs after 3 days.
Sikhism

- In the Sikh belief, there is only one God.
- All human beings are equal; therefore, harmony and non-violence are expected.
- Basic principles of life include meditation, work, charity and service to God and others.
Sikhism (continued)

Five religious symbols of faith often worn by devout Sikhs (the 5 Kakkas):

1. **Kesh** - uncut hair - maintain God given gifts; respect nature
2. **Kangha** - wooden comb - maintain body in clean/healthy state
3. **Kara** - iron bracelet - Sikh is slave to God, will do His works
4. **Kirpan** - short sword - soldier to protect weak and needy
5. **Kachera** - undergarment - reflects modesty and control
Sikh Beliefs about Illness

- Sikhs may consider their illness to be the will of God, but they also try to get well by adhering to medical advice.
- Ill patients pray to God for help and for forgiveness of any wrongs they have done.
General Concepts to Consider in Sikh Beliefs

- May prefer a health care provider of the same gender as the patient.
- Sanctity of human body is assumed; therefore, euthanasia is not endorsed, but needlessly prolonging a dying person’s life is discouraged.
- At the time of death, the preference may be for the head to be covered and for their religious symbols to remain on their bodies.
- Cremation is a usual practice.
Western Religions

- Judaism
- Christianity
- Islam
Judaism

- 5 branches—Hasidism, orthodox, conservative, reconstructionist, reform—encompass a wide variety of beliefs.
- Important themes include creation, revelation, and redemption.
- Only one God, who made everything and who seeks to save human beings.
- Imperative to follow God’s commandments, especially to love God and others.
General Concepts to Consider in Judaism Beliefs

- Mourners may make a small tear in clothes or wear a ribbon or ripped garment as sign of grief - deceased torn away from them.
- Body not left alone until burial, traditionally within 24 hours or sundown of the same day.
- Variable opinions about autopsy, organ donation or cremation so need to individualize to family's beliefs.
- Family may sit Shivah, observe mourning process and accept visitors.
Christianity

- Many branches include: Roman Catholic, Baptist, Lutheran, Anglican, Presbyterian, Eastern Orthodoxy.
- Unifying believes include belief in the Trinity, resurrection of the body and an afterlife of either eternal happiness or eternal torment, based on whether one lived a good life. (Trinitarian denominations)
- The most important commandments are to love God and to love others.
Christianity: Non Trinitarian denominations

- Christian Scientists - often view diseases as a mental health or emotional problem and the sick treated by prayer to correct illusions of bad health.

- Jehovah's Witnesses - Do not believe in blood transfusions and may practice conscientious objection to military service.

- Latter Day Saints (Mormonism)

- Unitarian universalis\ites

- Iglesia I Cristo (Church of Christ)
Christian Practices at the Time of Death

- Euthanasia 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.
- After death, the body is to be treated with respect.
- Organ donation may be acceptable to most denominations but may not be acceptable to an individual family.
- Funeral practices vary by denomination.
- Some denominations endorse cremation; all support burial.
Muslims and Islamic Beliefs

- Belief in Allah who is the one God and creator of everything.
- Prophet Muhammad received the Qur’an (sacred text) from angel Gabriel.
- Five school of Islamic though – religious beliefs will have different nuances.
- Cultural differences within the US among those who are African American, Southeast Asian or Arabic.
- These cultural differences influence views on viability and end of life.
5 Pillars of Islam Beliefs

1. Declaration of faith (Shahada) – one God and prophet and Mohammad is His messenger
2. Prayer facing Mecca 5 times each day
3. Almsgiving of at least 2.5% of income
4. Fasting during month of Ramadan
5. Pilgrimage to Mecca at least once in lifetime
Muslim Practices at the Time of Death

- Religious traditions led by the Imam who is spiritual leader.

- Muslims may vary in beliefs about cremation, autopsy or organ donation so it is important to ask.

- Since they may believe in resurrection, there may exist a preference that the body remains intact and this may influence response to autopsy request.

- Sects that follow ahadith, strive to bury as soon as possible after the death.
Role of the Chaplain

- Chaplains make a spiritual assessment and develop a plan of care:
  - based on patient and family needs,
  - with sensitivity and respect for individual spiritual beliefs and practices.

- Chaplains do not have a religious agenda and do not proselytize.
Training for Chaplains

- Most chaplains complete a course in Clinical Pastoral Education (CPE) a nationally accredited training program for pastoral and spiritual care in clinical context.

- Requirement for Board Certification as a Chaplain:
  - 4 units of CPE (1600 hours)
  - master’s degree in religious studies/theology
  - faith group endorsement
Chaplain as Vital Member of Interdisciplinary Team

- Any member of the clinical team should feel comfortable doing a basic screen for spiritual beliefs that support coping- Spiritual Generalist.

- The chaplain can provide a more thorough spiritual assessment- Spiritual specialist.

- The health care provider does not need to ask permission first.

- If you think it may be helpful for the patient and family, call the chaplain!
Components of Spiritual Support

- Compassionate, empathic listening and a “ministry of presence”
- Exploring questions of meaning and faith in relationship to illness and suffering (with parents and adolescent patients)
- Use of prayers, sacred texts and rituals from the patient’s and family’s tradition
Components of Spiritual Support (continued)

- Spiritual guidance with difficult medical decisions, including end-of-life care
- Support from the patient’s and family’s own clergy and members of their faith community
- Communicating with members of the interdisciplinary team about spiritual aspects of the patient’s and family’s coping, especially when differences arise with regard to treatment goals
Chaplain as Spiritual Interpreters and Educators

- Provide resources about:
  - How spirituality can support positive coping
  - Role of spirituality in decision making
  - Comforting rituals and practices

- Consider shadowing a chaplain and see what they do and how a spiritual plan of care is developed and carried out.

Koenig H, Spirituality in Patient Care (2008)

Association for Professional Chaplains’ online reading room.

www.professionalchaplains.org
The following cases will provide opportunities for further discussion concerning spirituality.
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 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?
Case 1: Points to consider:

- What discussion would you want to have with the family?
- What resources could you access to assist with their request? How would you find an Imam?
- How would you navigate this request from the perspectives of the child’s parents, nursing staff, child life and chaplain?
Case 2

Your patient is a 17yo African American female whose family’s Christian faith is vital to their daily life. Her family has rejected the medical team’s recommendation to discontinue aggressive treatment for her leukemia after a failed bone marrow transplant. She was admitted in acute respiratory distress and was intubated emergently. They report that they are relying on God to intervene with a miracle and ask you to continue doing everything. Your patient is requesting that no further treatment be initiated.
Case 2: Points to consider:

- What are your thoughts about this case?
- What additional insights into the family’s religious beliefs may be helpful?
- 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.
Case 3: Points to consider:

- How would you approach the issue with the parents?
- What discussions would you want to have with the cardiothoracic surgeon?
- How do you balance the rights of the parents with the rights of the infant?
- What additional resources might be of help to you?
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.
Case 4: Points to consider:

- What might be your reaction to their request?
- How might your religious background/beliefs influence your approach?
- What other resources might be available to you?
Case 4 (continued)

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:

- What might be your reaction to their request?
- Would it matter what your religious background/beliefs are?
- Any guiding principles that would be important to you?
- What additional team members might be helpful to include?
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 discontinue life support and you are preparing the family.
Case 5: Points to consider

- What questions might you ask them to understand their spiritual or religious beliefs?
- What other team members would you involve?
- Any additional thoughts about this case?
Case 6

You have served as the primary care provider for a 4 year old female child since birth. The child died this morning from complications from a genetic disorder. The family asks you to attend the funeral of their child.
Case 6: Points to consider

○ What is your initial response?
○ Would it matter what your religious/background beliefs are?
○ Would it matter what religious tradition they practice?
○ What additional information might you seek?
○ What are ways in which you could prepare for the experience?
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 understandably distraught because of the suddenness of these tragic events. She states that in their Judian religious beliefs, a family member must remain with her child’s body until taken to the funeral home.
Case 7 Points to Consider

- How might you approach this request?
- What resources would you want to access within the hospital setting to try to honor this request?
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- How might you approach this request?
- What resources would you want to access within the hospital setting to try to honor this request?
Common Themes and Key Points

- Spiritual humility by all health care providers is critical.
- A patient and family should be asked about religious traditions and rituals in addition to cultural beliefs.
- Providers should honor these requests within the hospital setting if at all possible.
- Inclusion of a chaplain should be routine.
Discussions concerning autopsy and organ donation must be individualized to the family and considered within religious beliefs and the broader family context and culture.

Strive to determine the family’s wishes concerning spiritual rituals at the end of life.

Clarify issues such as family presence with the body, timing of rituals and funeral, which have implications for the timing of an autopsy.
Conclusions

- Acknowledging and understanding the spiritual beliefs of patients and families is critically important in health care.
- Not all members of a specific religious tradition hold the same beliefs so respectful inquiry is essential.
- Health care providers need to practice as spiritual generalists and demonstrate spiritual humility.
- Subsequent referral to spiritual specialist will provide patients and families maximal support.
References

• American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care; Palliative Care for Children. *Pediatrics* 2000;106:351-357.


References (continued)

Online Resources

• Online “Reading Room” for the Association for Clinical Pastoral Education
  http://www.professionalchaplains.org/content.asp?contentid=100

• Cultural and Spiritual Competency
  http://www.healthcarechaplaincy.org/docs/publications/landing_page/cultural_sensitivity_hand

• Professional Chaplaincy: Its Role and Importance in Healthcare
  http://www.professionalchaplains.org/content.asp?admin=Y&pl=160&sl=83&contentid=162

• Collaboration among healthcare discipline can shape future understandings of how person cope with religion
  http://www.professionalchaplains.org/files/resources/reading_room/religion_health_healing_sp
  irit_fall08.pdf

• Common Standards for Professional Chaplains
  http://www.professionalchaplains.org/files/professional_standards/common_standards/commo
  n_standards_professional_chaplaincy.pdf