Spiritual Care of Patients with Advanced Illness: Associations with Quality of Death and Medical Care at the End of Life

Practical Aspects of Palliative Medicine 2017

Tracy Balboni, MD, MPH
Dana-Farber Cancer Institute
Center for Palliative Care Research
Department of Radiation Oncology

Katrina Scott, MDiv, BCC
Oncology Chaplain
Massachusetts General Hospital

Talk Outline

1. Tracy Balboni: Historical background and research informing spiritual care of patients with advanced illness
2. Katrina Scott: Practical aspects of spiritual care provision

Historical Background

- Currently: spirituality and medicine largely separate
- Important caveats:
  - Not for all healing traditions (e.g., Chinese medicine, shamanism etc)
  - Not the case until roughly 1700 to present
“The experience with this patient is a disturbing illustration of the care received by many terminally ill patients in U.S. hospitals – the site of death for 65 percent of the population. Despite repeated requests that he receive no further diagnostic interventions or life-prolonging treatment and that he be allowed to return home to die, the patient underwent a lung biopsy, three CT studies, daily phlebotomies, and insertion of multiple nasogastric tubes, as well as a gastrostomy tube. He was tied to a bed for 29 days so he would not remove the intravenous lines or feeding tubes, and he spent the last month of his life in the hospital. Recent reports suggest that his case, unfortunately, is not unusual.”

“First, the dying person confessed and then received the sacrament of extreme unction from the cleric who had heard confession and had absolved him. The administration of holy oil occurred on the traditional places of the five senses and the other bodily areas considered to be suffering... Some brethren remained with the dying inmate throughout the day and night, praying and reading from the Scriptures by candlelight. The point of this vigil was to ensure “proper passing”; nobody should be left to die alone. If death became imminent, the whole monastic community was summoned and the monks congregated around the sick on both sides of the bed alternately to pray and sing.”

Where Philosophy Meets Human Experience, Morrison et al NEJM

Where Philosophy Meets Human Experience

Where Philosophy Meets Human Experience
Research Informing Spiritual Care of Patients with Advanced Illness

Question 1:

Is religion/spirituality important to patients with advanced illness? What roles does it play?
Coping with Cancer Study (n=343):

“How important is religion to you?”

Religion and Spirituality in Cancer Care

- 75 randomly selected patients receiving palliative RT (RR=73%) in 4 Boston centers
- 78% religion and/or spirituality important to advanced cancer experience

Qualitatively-grounded religious/spiritual themes in patients’ experiences of advanced cancer, n = 53*

<table>
<thead>
<tr>
<th>Theme</th>
<th>n (%)</th>
<th>Representative Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping through R/S</td>
<td>39 (74)</td>
<td>I don’t know if I will survive this cancer, but without God it is hard to stay sane sometimes. For me, religion and spirituality keep me going.</td>
</tr>
<tr>
<td>R/S practices</td>
<td>31 (58)</td>
<td>I pray a lot. It helps. You find yourself praying an awful lot. Not for myself, but for those you leave behind. There will be a lot more praying.</td>
</tr>
<tr>
<td>R/S beliefs</td>
<td>28 (53)</td>
<td>It is God’s will, not my will. My job is to do what I can to stay healthy—eat right, think positively, get to appointments on time, and also to do what I can to become healthy again like make sure that I have the best doctors to take care of me. After this, it is up to God.</td>
</tr>
<tr>
<td>R/S transformation</td>
<td>20 (38)</td>
<td>Since I have an incurable disease that will shorten my life, it has made me focus on issues of mortality and sharpened my curiosity on religion/spirituality and what the various traditions have to say about that. I’ve spent a lot of time thinking about those issues, and it has enriched my psychological, intellectual, and spiritual experience of this time.</td>
</tr>
<tr>
<td>R/S community</td>
<td>11 (21)</td>
<td>Well, I depend a lot upon my faith community for support. It’s proven incredibly helpful for me.</td>
</tr>
</tbody>
</table>
Patient Religiousness/Spirituality

Silvestri et al. *Journal of Clinical Oncology*, 2003
- 100 pts with advanced lung cancer, their caregivers, 257 medical oncologists
- Rank 7 factors important to patient in making treatment decisions

Faith in Medical Decision-making

7 factors ranked:
- Oncologist’s treatment recommendation
- Ability of treatment to cure disease  #1
- Side effects
- Family doctor’s recommendation
- Spouse’s recommendation
- Children’s recommendation
- Faith in God  #2 for pts/families, #7 MDs

Faith in Medical Decision-making

CWC study: Relationship between religious coping and receipt of aggressive medical care at the EOL
Question 1: Is R/S important to patients with advanced illness?

- Important to most patients, particularly ethnic minorities
- Plays multiple roles: coping, practices, beliefs, transformation and community
- Impacts medical care decision-making

Question 2:

What role does R/S play in patient well-being as they encounter advanced illness?

R/S and QOL

Brady et al. Psycho-Oncology 1999

- Multi-institutional cross-sectional study of 1610 cancer patients.
- R/S (measured by the FACIT-Sp) → independent predictor of QOL
- Controlled for physical well-being, emotional well-being, social well-being, disease, demographic variables
- R/S associated with improved symptom tolerance
R/S and QOL

Steinhauser et al. JAMA 2000
- National survey of 1885 seriously ill patients
- Importance of 44 attributes of quality of life near death
- 9 major attributes ranked

Factors Considered Important to QOL at EOL

<table>
<thead>
<tr>
<th>Attributes</th>
<th>Patients</th>
<th>Responded Family Members</th>
<th>Physicians</th>
<th>Other Care Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peaceful surroundings</td>
<td>3.27 (1)</td>
<td>3.29 (1)</td>
<td>2.39 (1)</td>
<td>2.52 (1)</td>
</tr>
<tr>
<td>At peace with God</td>
<td>3.15 (2)</td>
<td>3.11 (2)</td>
<td>3.82 (2)</td>
<td>3.71 (2)</td>
</tr>
<tr>
<td>Freedom from pain</td>
<td>3.09 (3)</td>
<td>3.35 (3)</td>
<td>0.64 (3)</td>
<td>2.00 (3)</td>
</tr>
<tr>
<td>Mentally aware</td>
<td>4.09 (4)</td>
<td>5.41 (4)</td>
<td>6.07 (4)</td>
<td>6.51 (4)</td>
</tr>
<tr>
<td>Treatment choices followed</td>
<td>5.01 (5)</td>
<td>5.37 (5)</td>
<td>5.15 (5)</td>
<td>5.14 (5)</td>
</tr>
<tr>
<td>Finances in order</td>
<td>5.03 (6)</td>
<td>5.12 (6)</td>
<td>6.02 (6)</td>
<td>7.41 (6)</td>
</tr>
<tr>
<td>Feel life was meaningful</td>
<td>5.08 (7)</td>
<td>5.53 (7)</td>
<td>5.62 (7)</td>
<td>4.06 (7)</td>
</tr>
<tr>
<td>Peaceful conflicts</td>
<td>5.03 (8)</td>
<td>5.35 (8)</td>
<td>5.31 (8)</td>
<td>5.39 (8)</td>
</tr>
<tr>
<td>Die at home</td>
<td>7.03 (9)</td>
<td>6.19 (9)</td>
<td>6.76 (9)</td>
<td>7.16 (9)</td>
</tr>
</tbody>
</table>

*Attributes are listed from highest to lowest, based on patient response. Numbers in parentheses are median scores. Higher scores indicate less important attributes and higher median scores indicate less important issues at the end of life. Values in parentheses indicate the median rank based on patient response. Higher values indicate less important attributes."*

Question 2: What role does R/S play in patient well-being with illness?
- Important to pt well-being
- One of the most important issues at the end of life.
Question 3:

Does advanced illness raise spiritual concerns or needs? What are they?

Spiritual Issues in Advanced Illness

Religion and Spirituality in Cancer Care
- 75 randomly selected patients receiving palliative RT (RR=73%) in 4 Boston centers.
- 14 spiritual issues assessed
- 85% 1 or more spiritual issues
- Median of 4 spiritual issues

Quantitatively-assessed religious/spiritual concerns in advanced cancer

<table>
<thead>
<tr>
<th>Religious/Spiritual Beliefs</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doubting one’s belief in God or one’s faith</td>
<td>13 (19)</td>
</tr>
<tr>
<td>Questioning God’s love*</td>
<td>14 (21)</td>
</tr>
<tr>
<td>Questioning God’s power*</td>
<td>14 (21)</td>
</tr>
<tr>
<td>Believing the devil caused the cancer*</td>
<td>6 (9)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religious/Spiritual community*</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling abandoned by ones religious/spiritual community*</td>
<td>6 (9)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religious/Spiritual transformation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling a closer connection with God or one’s faith</td>
<td>36 (53)</td>
</tr>
<tr>
<td>Seeking what gives meaning to life</td>
<td>37 (54)</td>
</tr>
<tr>
<td>Seeking forgiveness (of oneself or others)</td>
<td>32 (47)</td>
</tr>
<tr>
<td>Feeling angry at God</td>
<td>17 (25)</td>
</tr>
<tr>
<td>Feeling abandoned by God*</td>
<td>19 (28)</td>
</tr>
<tr>
<td>Feeling punished by God*</td>
<td>15 (22)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religious/Spiritual coping</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeking meaning in the experience of cancer</td>
<td>34 (50)</td>
</tr>
</tbody>
</table>
Question 3: Does advanced illness raise spiritual concerns or needs?

- Yes, for most
- Most with multiple spiritual issues

Question 4:

Do patients with advanced illness want their medical care to include attention to R/S dimensions?

Patient Desires for Spiritual Care

- Importance of oncology MDs/nurses “considering patients’ spiritual needs as part of cancer care”
- Four response options:
  - Not at all important
  - Mildly important
  - Moderately important
  - Very important
Patient Preferences for Spiritual Care in Advanced Cancer

- MDs: 89% at least ‘mildly important’ (65% ‘moderately’ or ‘very important’)
- RNs: 87% at least ‘mildly important’ (69% ‘moderately’ or ‘very important’)
- 9% received spiritual care from MDs, 20% from RNs
- 8 spiritual care types included: spiritual history, referrals to chaplains

Do patients with advanced illness want medical care to include R/S?

- Yes, most do
- Spiritual care is infrequent

Question 5:

Does spiritual care in the medical setting benefit patients with advanced illness?
Coping with Cancer (CwC) Study

- Multi-site, prospective study of advanced, incurable cancer pts, N=343
- Purpose: examine psychosocial/spiritual factors and relationship to EOL outcomes

Results: Spiritual Care and QOL Near Death

Results: Spiritual Care and EOL Medical Care

High spiritual care from medical team (nurses, chaplains, MDs, etc):
- Greater hospice: ~3-fold greater odds
- Less aggressive EOL care: (e.g., ICU care, resuscitation) ~3-fold reduced odds
Conclusions

- Religion/spirituality play multiple roles in experience of advanced illness (QOL, medical decision-making, etc)
- Multiple types of spiritual concerns common
- Spiritual care influences patient well-being and medical decision-making

Why ME?

Addressing Spiritual, Religious and Existential Needs of Oncology Patients/Families

Presentation Overview

- Meaning & Practice of Spiritual Care
- Spiritual Concerns
- Pain/Suffering
- Interventions
- Awareness/Competencies
National Consensus Project’s Practice Guidelines for Quality Palliative Care includes Eight Domains of Care.


Definitions of terms (spiritual, religious, existential) vary greatly

**Meaning & Practice**

**Spirituality:**
- That which allows a person to experience a sense of transcendence in life
- The web of relationships that gives coherence to our lives
- Connection to something greater than ourselves

EAPC Consensus Project Definition (International Conference, JPM 6-2014):

“Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices.”
Meaning & Practice

- **Religions** are organized and communal systems that provide specific frameworks for making sense of existence and responding to universal spiritual questions.

- Religious rites and rituals provide concrete ways of expressing shared beliefs and offer powerful sources of inspiration and comfort for many, while certain religious dogmas may have a harmful effect.

Meaning & Practice

- **Existential** themes usually present as “why” questions about human existence within a larger context. *(Boston & Bruce, 2011, JPSM)*

  They refer to the human condition and how we make sense of and respond to universal questions:

  – “Why am I here?”
  – “What is the purpose of my life?”

Meaning & Practice

- **Belief Systems** are a person’s core values used to understand everyday experience:
  
  “Belief systems are the stories we tell ourselves to define our personal sense of Reality… and it is through this mechanism that we individually make sense of the world around us.” *(Uso-Domenech & Nescolarde-Selva, 2015)*

- Each patient’s authentically expressed belief system should be accepted, affirmed and respected.
Meaning & Practice

- The relationship between spirituality and religion is that of the whole to the part.
- Spirituality, the larger more inclusive reality, may be expressed in traditional religious terms, in nontraditional religious terms or in humanistic terms. Spiritual care is appropriate even when patients/families identify little or no interest in religion.

Meaning & Practice

- During this presentation, I will be using “Spirituality” as an all inclusive term.

Meaning & Practice

PEW 2012 Report, “Rise of the Nones”

- 1/5 (20%) of people in US are unaffiliated with any religion
- While only 9% of people over 65 are unaffiliated, 32% of people under 30 are not looking to join a religion
- Growing number of people who identify as “spiritual not religious”
Meaning & Practice

PEW 2015 Report, America’s Changing Religious Landscape (35,000 Americans interviewed)
- http://www.pewforum.org/2015/05/12/americas-changing-religious-landscape/
- Christian share of the U.S. population is declining while the number of U.S. adults who do not identify with any organized religion is growing, occurring among Americans of all ages. The same trends are seen among whites, blacks and Latinos; among both college graduates and adults with only a high school education; and among women as well as men.

Meaning & Practice

- Spiritual, religious and existential wellbeing are considered major components of health-related quality of life (QOL).
- People find their spirituality helps them to cope with illnesses, traumas, losses, and life transitions by integrating body, mind and spirit.

Meaning & Practice

- Joint Commission’s Mandate: “Patients have a fundamental right to considerate care that safeguards their personal dignity and respects their cultural, psychosocial, and spiritual values.” (JCAHO, 1998)
- Since 2004, the Joint Commission has required a Spiritual Assessment of each hospitalized patient as a standard of care.
New Question:
Who will provide spiritual support in U.S. healthcare facilities to the “Nones” and unaffiliated?

Meaning & Practice

There are many well-established interviewing tools for screening, assessing and evaluating a patient’s belief system:
(Cadge & Bandini, Society 2015)
- Screening
- Spiritual History
- Spiritual Assessment

Meaning & Practice

Screening Tool: one or two open-ended questions you’re comfortable asking
- Where do you find strength during difficult times?
- Are you often at peace at the end of the day?
- Do your personal beliefs help you in making sense of your illness?
Meaning & Practice
Among the most well-known tools for taking a spiritual history is the 4-point **FICA** tool:
- Faith/religious affiliation
- Importance/Influence of beliefs
- Community involvement
- Addressing issues in providing care

Meaning & Practice
Example of introducing the **FICA** tool:
“We’ve found that many people have spiritual or religious beliefs that guide them in making medical decisions. It’s our practice to ask our patients a few questions to help us know you and your preferences better, especially if you were to become seriously ill. This will just take a minute or two.”

Meaning & Practice
And the **HOPE** spiritual history tool:
- Sources of Hope, meaning, comfort, strength, peace, love, compassion
- Organized religion
- Personal spiritual practices
- Effects on medical care and EOL care
Meaning & Practice

Example of introducing the HOPE tool:
“Our practice recognizes that patient-centered care includes caring for the whole person. Would you be comfortable in answering a few questions about sources of strength and support that help you through difficult times?”

Meaning & Practice

The FACT spiritual assessment tool:
- Faith/belief system or practices
- Active/availability/accessibility
- Coping (comfort)/Conflict (concern)
- Treatment plan (coping well/poorly)

Meaning & Practice

Example of introducing the FACT tool:
“I wonder how you’re coping with all that’s going on with your health. It’s normal for many folks to examine their personal beliefs, especially when facing a life threatening illness. So I’d like to ask a few questions to better understand how to help you.”
Meaning & Practice

- Spiritual care is an integral and vital component of oncology clinical practice.
- The multi-disciplinary team needs skill in supporting patients/families in various traditions/belief systems throughout the course of illness.

Meaning & Practice

- Most frequent qualitative questions reflective of oncology patient’s deep-seated spiritual, religious and existential needs (Strang & Strang, 2002; Sulmasy, 2006)
  - Meaning/Purpose
  - Death/Dying
  - Illness/Pain
  - Value/Dignity
  - Relationships/Reconciliation

Suffering

- Eric Cassell (The Nature of Suffering and the Goals of Medicine) defines suffering as a state of severe distress associated with events that threaten our personhood, a feeling that “what ought to be whole is being split apart”.
- Suffering continues until the treat of disintegration has passed or the integrity of the person is restored, generally by restoring a sense of meaning and wholeness.
Suffering

- It’s at these transition points, from wellness to illness when there is greater uncertainty about what lies ahead, that change happens.
- This may lead to introspection, growth and transformation (positive spiritual coping) or dread, fear, despair (negative spiritual coping).

Spiritual Pain/Suffering

- Patients rarely voice spiritual concerns until distressing physical, emotional and social problems are alleviated.
  – Abraham Maslow’s Hierarchy of Needs: dependence of higher on lower needs. The apex of the pyramid suggests that higher needs are less frequently met.

---

Hierarchy of Needs

- **Physiological/Basic Biological Needs:** Food, drink, shelter, sleep
- **Safety:** Law, security, stability
- **Love/Belonging:** Family, affection, relationships, work
- **Esteem/Achievement:** Status, responsibility, reputation
- **Self Actualization:** Awareness, meaning

---
**Spiritual Pain/Suffering**

- **A. Maslow’s Hierarchy of Needs as disease progresses.** (R. J. Zalenski & R. Raspa, 2008)
  - Physiological: biological needs, pain & symptom control, restoring ability to meet life needs (eating, breathing)
  - Safety: Free of fears of dying, choking, drowning
  - Love & Belonging: re-affirmed by family caregivers despite illness
  - Esteem: respect for past and present (infinite) value of person
  - Self-actualization: personal journey, growth in illness, connection to “other” peace, transcendence, closure

---

**Self Actualization:**
- Transcendence, personal growth

**Esteem/Achievement:**
- Respect for past and present value of person

**Love/Belonging:**
- Reaffirmed by family caregivers despite illness

**Safety:**
- Free of fears of choking, drowning, painful death

**Physiological/Basic Biological Needs:**
- Pain & symptom control, meeting life needs

---

**Spiritual Pain/Suffering**

- Spiritual Pain frequently manifests as physical symptoms, which patients may perceive as more acceptable to clinicians.

- Spiritual Pain often shares features with depression: pervasive guilt not connected to a particular event, feeling hopeless and worthless and a sense of meaninglessness.
In a recent study of 1156 physicians, 81% agreed that "patients with spiritual struggles tend to have worse physical pain" and 88% stated they should seek to relieve that suffering just as much as physical pain. (Smyre et al, JPSM 2015)

However many clinicians, especially physicians, continue to be slow in acknowledging and responding to these needs.

Spiritual Pain/Suffering often occurs:
- When people become “stuck” in asking “why” questions that can’t be answered
- When a person’s belief system is shattered
- When facing issues of forgiveness or regret
- When facing issues of guilt or punishment
- When a patient is fearful: of death, pain, the unknown, etc.
- When a patient or family feels totally helpless/having no control
- When a patient or family loses hope
- When a patient or family are unable to attend services as disease progresses
Spiritual Pain/Suffering

- In some cases, beliefs, practices and worldviews may contribute to spiritual pain. Examples include doctrines that threaten patients with eternal punishment for certain behaviors or beliefs. Feelings of guilt, low self-esteem and worthlessness often accompany such worldviews.
  - "I'm gay; my father says I'm going to hell.
  - "I didn't pray enough and she died.
  - "A miracle will happen if his soul is clean.

Interventions:

- Goal of intervention:
  To alleviate suffering by helping patients/families to develop a sense of meaning that allows them to transcend their current situation by making sense of it.

Interventions:

- Spiritual healing is often possible when sources of pain are identified and specific interventions are applied.
  - Acknowledge their suffering
  - Explore "why"
  - Provide an empathic presence through reflective listening
Interventions:

- Just as you would respond to a patient's somatic complaint (severe stomach cramps) by first acknowledging their pain and then exploring their symptoms, you need to first acknowledge and then explore spiritual pain/distress.
- It's important you respond in a non-judgmental way by referencing the patient's beliefs, not your own.

Interventions:

- The “why” question is one of the best predictors of distress. It’s based on uncertainty about the future, worry, fear, grief and loss.
- It also presents the perfect opportunity to explore and assess the patient’s belief system and how those beliefs may help or hinder coping.

Case of Mr. C

- Mr. C is a 74 year old gentleman with worsening symptom burden due to multiple comorbidities associated with his disease progression (colon cancer). During your visit with Mr. & Mrs. C, he simply states: “I’ve been a good person, and tried my best for my family. Why is God punishing me?”
**Interventions:**
- Example of acknowledging and validating his question (which is indicative of *negative spiritual coping*):
  - It’s very painful to feel that way. It sounds like you’ve given this a lot of thought: could you tell me more? (tell-ask-tell)
  - Yes, it’s true: you are a good person. I know you’ve devoted yourself to your family and that’s something you value. Could you tell me more? (tell-ask-tell)

**Case of Mr. C**
- After Mr. C shares his spiritual concerns, his devoted wife Mrs. C states: “Don’t worry honey… we’re all praying for a miracle and I know God won’t let us down.”

**Interventions:**
- There are many ways to address “miracle” statements... let’s try to re-frame these statements in a more positive light. ([Delisser, Chest 2009](#))
  - People use miracle statements in desperate times; they are *not* necessarily in denial. Such statements indicate they are aware of the severity of the situation.
**Interventions:**

“I know you understand how serious your husband’s health is at this time. This must be very difficult for you both.”

(Acknowledges that you understand her concern and credits her assessment of how serious the situation is while inviting them to share more of their fears.)

**Interventions:**

– Miracles have different meanings to different people; sometimes it’s asking for divine intervention or may simply reflect the patient’s/family’s values and beliefs that they’ve turned to for support in difficult times. It may mean a medical miracle not dependent on a higher power; you’ll never know until you ask! Explore what the miracle might look like while respecting world views that may be quite different than your own.

**Interventions:**

“I understand you’re praying/hoping for a miracle and it would be wonderful if that happens. But if that’s not to be, what else would you pray/hope for?”

(Affirms/respects their belief system while asking them to face their fears through reframing and developing other hopes.)
**Interventions:**

**Important thoughts:**
- Spiritual interventions are rarely precise/tidy
- When faced with a patient’s spiritual pain, you’re initially likely to experience a sense of dismay and helplessness. Good! That’s what empathy is (“walking a mile in your shoes”). If you feel this way, imagine how they feel!
- It is from this empathic response that spiritual support can often be most effective

**Interventions:**
- Most effective healing agents you as a clinician can provide:
  - Acknowledge the presence of spiritual pain
  - Provide a caring presence
  - Listen attentively to the patient’s life story
  - Involve a chaplain/spiritual care specialist

**Interventions:**
- Good spiritual care uses the patient’s and/or family’s personal goals as measuring sticks, not our own.
  - Try to be non-judging
  - Meet the patient and family where they are by asking: “What’s most important to you at this time?”
Interventions:
- Spiritual support, especially during times of moral distress, bereavement and loss, is not limited to patients and families but available to every member of the multidisciplinary team of caregivers:
  - Debriefing/staff support (ethical dilemmas, patient/family dynamics, compassion fatigue, demoralization, etc.)

Awareness/Competencies
- Recognize that everyone has a spiritual dimension
- Recognize that some folks have specific religious needs
- Recognize your own personal boundaries and limitations in providing spiritual care
- Recognize when to place a referral to a Chaplain/Spiritual Care Specialist

Awareness/Competencies
- Recognize that spiritual needs require acknowledgement
- Have an awareness of your own spirituality/belief system
- Have respect for patient’s world view that may be quite different than yours
Awareness/Competencies

- Understand the importance of confidentiality and when to disclose and document information
- Understand the importance and impact of non-verbal and verbal communication
- Understand oncology patients often equate “letting go” as “giving up”

Awareness/Competencies

- What examples can you give where you felt that spiritual need was a part of the overall care of a patient?
- How did you feel when you responded to an issue raised by a patient or caregiver which you felt was spiritual by nature?

Awareness/Competencies

- What has made you aware that a patient may have religious needs?
- When would you place a referral to the Chaplain/Spiritual Care Specialist?
- What help do you need to develop your competencies in this area of care?
Awareness/Competencies

- Important to remember: As clinicians involved in a dying person's care, we must understand we are not responsible for giving patients meaning, value or reconciliation but are able to facilitate the connections that are already present in that patient's life.

Awareness/Competencies

- Always remember:
  
  *We are good but we are not God.*

Last Thought:

“If we want to support each other’s inner lives, we must remember a simple truth: the human soul does not want to be fixed, it wants simply to be seen and heard.”

*Parker Palmer, The Courage to Teach*
Case:

Mrs. G is a 45 year old woman with Stage IV NSCLC who has been actively engaged in treatment since her diagnosis 3 years ago. During this time, she has slowly but steadily declined physically, with weight loss, fatigue, back and joint pain and multiple issues related to her diagnosis. She has had a depressed mood that has been treated with citalopram. After 3 weeks, Mrs. G began experiencing headaches and was diagnosed with the brain metastases and has been receiving whole brain radiation.

Case:

Last week she was admitted with worsening symptoms. Late at night you are paged to her room. Upon entering, Mrs. G is in tears: “Enough is enough… I’m so tired.” During the next half hour, Mrs. G describes how active she had been until her illness; an avid jogger and self-described “exercise nut”, she has been unable to do any type of physical activity for the last 2 years, and currently uses a walker just to get around the house.
Case:

Married with two daughters aged 10 and 8, she and her family live on the first floor of a two family house they have shared with her in-laws since her diagnosis. An only child, Mrs. G always wanted to have children and now she has given up most of her duties as a mother and homemaker to her mother-in-law, unable to attend any school functions or religious services with her family because of her chronic pain. “I don’t want to live like this anymore but I know my family won’t let me consider giving up.”

Case:

They tell me “The girls need a mother: how could you think about doing that to them? What good would killing yourself do?” I’m scared about dying but just look at me… I don’t even look like me anymore… I’m a shadow. My husband and his mom tell me that a miracle could be just around the corner. It’s probably wrong just to think about it [stopping treatment] but haven’t I been punished enough? So many questions… Would it be a sin to stop the treatment? What did I do to deserve this? Is God really punishing me? I just don’t understand.