PART I: HOW TO ASSESS SPIRITUALITY

When to Ask

Assessment of religious/spiritual frameworks and needs by physicians, nurses, and other care providers can take place at various stages during the course of a relationship with a patient and family:

- In the course of non-crisis care
- At the time of initial diagnosis of life-threatening illness
- At the time of admission to hospice/palliative care
- In response to signs of spiritual suffering, possible indicators of which include:
  - Fear
  - Hopelessness
  - Guilt
  - Asking questions such as "Why hasn't God taken me yet?" or "What have I done to deserve this?"
- As complex treatment decisions are faced regarding:
  - Artificial nutrition
  - Use of radiation or chemotherapy
  - Removal of life support
  - Use of antibiotics
- When the time of death draws near

What to be Prepared for When You Ask

Assessment of religious/spiritual beliefs and needs is an exceedingly elusive and sensitive area. These may be considered to be very personal questions

- Do not be surprised if you encounter some initial resistance or mistrust, especially if the patient/family adheres to a religious tradition with a history of persecution
- Although patients and families want their physicians and nurses to take interest in this area, you are seen as experts in medical science primarily. You may even be perceived as threats to the experiential knowledge of the spiritual realm and to religious authority

  For Example: *Persons with a strong belief in faith healing may respond to news of their terminal illness by saying, "What does the doctor know anyway, he's not God"*
  Some spiritual traditions accept the need for specific treatments by Western medicine -- such as surgery to remove a tumor -- but would look to their own healing practices for treatment of other diseases such as a "weak heart"

- During your visit with a patient and family, physical and medical needs will demand most of your time and attention
  - Little room may be left for discussion of spiritual issues if the patient:
    - Is in physical pain
    - Has received an overload of medical information related to treatment options and prognosis
  - Possible ways to address this include:
    - Consult with other members of the interdisciplinary team to learn about relevant religious beliefs
    - Plan to follow-up with the patient and family at a later time to discuss these issues

How to Ask - General Guidelines for Spiritual Assessment

- One approach is to ask one or two brief questions about spiritual/religious beliefs and needs in one or more of the following contexts:
  - Along with the social or lifestyle history
  - Following the discussion of terminal diagnosis

- As new, major treatment decisions are to be faced

  Case Example: *Mrs. T has just been informed by her oncologist that her breast cancer is no longer responding to chemotherapy and has spread aggressively to other parts of her system. Her doctor recommends hospice care to control the pain and to help her family care for her in the comfort of her own home. Mrs. T expresses concerns about how her adult children will take the news, "I just know this will devastate them." The doctor explains that the hospice team will help her family adjust and communicate about the news. She then asks, "Where do your children usually turn to during difficult times for support? Do your children have any spiritual beliefs or practices that might give them strength or hope?"*

- Another approach is to ask the patient and family what is most important to them during this time of illness and direct your questions to the area they indicate as highest value (e.g., my family, not being in pain, growing closer to God)
- It is best to begin with a statement that affirms the importance of this area for some, but not all persons and indicate its direct relevance to the medical care you are providing
- Open-ended questions are preferable
- Use a format that avoids stereotyping but draws upon generally established beliefs and practices of a spiritual/religious tradition
- Use language that is interfaith, not grounded in one religious or spiritual tradition
  - For example, use:
    - "Faith community" rather than "church"
    - "Religious leader" rather than "priest"
    - "Higher power" rather than "God"
  - Ask about sources of strength and hope, important customs, practices, and beliefs
  - Listen for “cues” from patient and family and use their language whenever possible
- Avoid judgment of religious/spiritual practices and beliefs
- Refrain from extensive intellectual exploration of specific religious doctrines and dogma
- Be aware of your own framework, biases, and comfort zone in this area
- Recognize limits of expertise, time, and role; know when to refer to a professional spiritual caregiver or chaplain
- Respect patient/family/cultural privacy in this area

Assessing the Significance of Religious Beliefs and Practices

Asking About Religious Affiliation: Benefits and Limitations

- That a person counts themselves a member of a faith community or religious tradition tells you little about:
  - What they actually believe and practice
  - How their beliefs and practices may influence their health care decisions at the end of life
- Persons who are alienated from their religious tradition or who have long considered themselves to be “non-practicing” often discover, much to their dismay, the profound impact their earliest religious formation has on their experience of coping with a terminal illness and facing dying and death
- Other persons may consciously seek reaffiliation with, or embrace certain practices of, their faith tradition at this time of crisis; death bed “conversions” are not unheard of as persons face one of life’s ultimate events
- The extent to which this newfound religiosity penetrates the corners and crevices of a person’s consciousness directly influences the role it will play in decisions about end of life care not to mention the level of comfort it may bring that person
- In countries such as the United States that boast religious and cultural diversity, family members may have different and even conflicting beliefs and values that impact decisions about end-of-life care

  For Example: *Considered in the abstract, the Jewish and Christian belief that each human person is created in the divine image both permits and limits the use of life-prolonging medical interventions. On the one hand, if human life is a divine and not a human creation, “doctors should not play god.” On the other hand, that human life is sacred establishes a moral foundation to preserve it, sometimes at all costs*.

Goals of the Assessment

Goal 1: Gaining a Personalized Understanding

To gain a "personalized" understanding of a patient's and family's religious/spiritual framework so as to determine how these beliefs and values may influence decisions regarding end-of-life medical care. A "personalized" understanding requires you learn about:

- The unique way "traditional" religious teachings have been appropriated, interpreted, and applied within a patient's or family's cultural subgroup and life story

  Case Example: *Joe attends weekly Catholic mass, receives sacraments, and wants the priest to do his funeral service even though he disagrees with what the official church has to say about his homosexuality.*

  Case Example: *Mary considers herself a Christian Scientist yet has always sought Western medical care for her cancer, including surgery and chemotherapy.*

- The weight or importance this spiritual/religious framework holds for them at this particular stage in their life and illness
  - Some people return to the religious schooling of their youth as they face their own death, others do not
  - Many persons will consider themselves members of a specific religious tradition, may observe certain religious rituals and holidays, yet have not integrated the beliefs and values into their everyday living or views about illness, death, and dying

- Conflicting or competing sets of values and beliefs that may limit the impact of the religious framework

  Case Example: *Although Mrs. Smith's religious tradition teaches that physical life is not all there is and even professes "man does not live by bread alone," she is the matriarch of a large Italian family whose primary responsibility has been to show love and sustain life in and through food. She therefore insists that her daughter have a feeding tube placed when the cancer takes away her appetite and makes it hard for her to swallow.*

  - Remember that the need a patient or family has to prolong physical life may in fact result from psychological causes or family dynamics rather than religious beliefs per se, such as:
    - Fear that the death will cause instability to family roles
    - Unresolved grief
    - Unfinished business

Goal 2: Respecting Beliefs and Practices

To respect beliefs and practices related to healing, dying/death, and life after death and to affirm these as resource for patient and family coping

- Like cultural traditions, religious and spiritual traditions may define how persons understand:
  - Health
  - Life
  - Healing
  - Illness
  - Death
- In addition, religious and spiritual traditions offer persons ways to:
  - Make sense of suffering
  - Find strength and comfort
  - Sustain hope even when there is no medical or human cure for illness
- Religious traditions may also offer ritualized means to:
  - Face the unknown and unpredictable
  - Resolve unfinished business
  - Face terminal illness and death
  - Affirm the value of human life
  - Provide hope of continued bonds with loved ones even after death

Goal 3: Ascertaining Unmet Needs

To ascertain unmet religious and spiritual needs and to determine patient and family interest in additional spiritual care. While many clergy are trained to meet the needs of their members at this critical point in life, many are also uncomfortable or unequipped to provide care and counseling in the face of life-threatening illness.

- Just because a patient/family indicates they are "non-religious" or "non-practicing" does not mean they do not have spirituality needs or a spiritual framework that informs their lives and health care decisions
- Recent polls indicate that of those persons with a connection to a faith community, under 50% felt they could turn there for spiritual care at the end-of-life

> **Case Example:** *Health care providers may observe that a patient is very anxious or fearful or may hear statements suggesting the existence of despair or self-blame such as, "I must have done something wrong to deserve this kind of suffering." The patients may not consider themselves as very "spiritual" and therefore may decline a visit from the "chaplain." However, these kinds of issues are rightly included as part of the spiritual assessment.*

Goal 4: Uncovering Spiritual Suffering

To uncover the existence of spiritual suffering, explore its causes, and develop a plan of care to lessen or alleviate it

- By definition, most patients and families experience spiritual suffering during this stage of their illness and life
- However, considerable variation exists among patients and families facing life threatening illnesses in terms of:
    - The degree of suffering
    - How physical pain and spiritual suffering are related
    - The underlying causes spiritual suffering
    - Means to address spiritual suffering

> **Case Example:** *Mrs. Kane had unrelieved nausea and vomiting from an obstruction in her bowel which caused her to feel as if God had abandoned her in her time of greatest need*

> **Case Example:** *Joseph refused to take his pain medication, even though he complained constantly to the nurses and doctors that his pain was unbearable. Upon further assessment, he confessed the belief that in order to "gain entrance into paradise" he must be purified of all his bad faults and ways through suffering here*

Sample Questions for Spiritual Assessment

Spiritual Assessment Goal #1:
To Understand Patient and Family's Spiritual/Religious Framework and its Impact on End-of-Life Medical Care

Questions to Learn About a Patient and Family's Spiritual/Religious Framework and its Level of Importance in Their Lives

- "What is your philosophy of life?"
- "Do you have a set of beliefs or values that form the lens through which you view yourself and others, which inform how you think about this stage of your life/your illness/your care?"
- "Do you consider yourself to be a spiritual person? A religious person?"
- "Are you affiliated with any certain religious tradition? How important is this tradition in your everyday life? What role does this play in dealing with your illness?"
- "On your admission form, it indicates that your religious affiliation is _____. How important is _____ to you? Is it important to you that we talk about how your spirituality relates to your illness/to your medical care/as you face treatment decisions?"
- "Many people have spiritual or religious beliefs that shape their lives, including their health and experience with illness. If you are comfortable talking about this topic, would you please share any of your beliefs or practices that you might want me to know as your [palliative care/hospice] physician /nurse?"

Questions to Identify Religious Beliefs and Authority that May Influence Decisions Regarding End-of-Life Care

- "To whom or what do your turn for support and guidance when faced with hard decisions?" Would it be helpful to contact them before we meet together with your family to decide about discontinuing chemotherapy/radiation/antibiotics/ artificial nutrition? As you consider shifting the focus of your care to comfort measures and relief of suffering?

- "You are facing a difficult decision regarding the direction of your medical care. Earlier you mentioned you were a "very religious person." Are there beliefs or teaching from your religious faith that you need to take into account as you make this decision? Are there practices or rituals (prayer, meditation, ritual cleansing, reading sacred stories or scripture) that would give you direction, insight, answers? Is there a religious leader or teacher you would like to consult?

- "Are there spiritual or religious beliefs you hold that conflict with the general philosophy or goals of palliative/hospice care I've just described? Does your religious faith have beliefs that will help you cope with this news/as your disease progresses?

- "It is my understanding that many _____(orthodox Jews, devout Muslims, Pentecostal Christians, etc.) believe that _____. Do you share this belief about prolonging/ sustaining life, regarding the relief of suffering, etc.?"

- "Although you mentioned you were not very strict or observant in your practice of _____, are there specific elements of medical care that you forbid on the basis of religious/ spiritual/cultural grounds? For example, dietary restrictions, specific treatments such as blood transfusions, autopsy, the use of sedating medications?

- "What does your spiritual/religious tradition teach regarding _____? Do you share this belief? What do you currently believe about _____? Does your family share your view?

Spiritual Assessment Goal #2:
To Respect Spiritual/Religious Beliefs and Practices and to Affirm These as a Resource for Patient and Family Coping

Questions to Learn About Specific Spiritual/Religious Practices to be Observed and Encouraged during time in Palliative/Hospice Care

- "Every patient and family in our care has their own set of customs and beliefs. We would like to be able to respect yours while you are in the hospital. Are there specific practices that you carry out as part of your spirituality/religion? (Prayer, meditation, journaling, music, reading of scripture, worship, massage, ritual cleansing, etc.) How can we assist you in sustaining these practices during your admission? Now that you are confined to your home/bed?"

- "I've noticed you seem (fearful, anxious, agitated, overwhelmed, confused, sad, despondent) since (we met with your family yesterday; you were transferred to the palliative care unit; you learned about _____). Have any spiritual or religious practices been helpful to you in the past when you've felt this way? Would praying/reading your Bible/singing/meditating bring you comfort/strength/hope?"

- "What will help sustain your spirit/give you strength during the days to come/as your disease progresses? Are there any activities or rituals that are old and familiar, help you feel like a whole person, bring you comfort, clear your mind, give you peace?"

Questions to Learn About the Meaning of Health, Illness, Death, and Life After Death

- "Earlier you told me you are praying for healing. What would that healing look like? Does healing happen only in the body or does it include other dimensions of your self?"
- "What do you think has caused your illness? Why have you become sicker at this time?"
- "What does your religious tradition teach about healing/illness/death? Do you agree with this view?"
- "You have been very honest with us about the fact you know you are dying and are not afraid. To help you and your family when that time comes, it would be helpful to know a little more about how you view your own death"

- Are there any spiritual or religious beliefs you hold about dying, death, or life after death that would be helpful for us to know as we care for you and your family?"

Questions to Identify Practices to be observed in Preparation for, at the Time of, and After Death

- "Are there any specific spiritual or religious practices you and your family would like to observe before you die/as you are dying/at the time of death (for example, prayers, chanting, anointing)?"

- "Are there any special instructions we should know about regarding the handling of your/your loved one's body, removal of your remains? For example, for many orthodox Jews transporting the body on the Sabbath is forbidden. For some cultures or religions, only members of the same sex are permitted to touch the deceased."

- "Is there a spiritual leader or clergy person we should contact for you at this time/at the time of death/to help you (the family) before the funeral home arrives?

- "Though not recently a practicing _____, you/your loved one was raised in the _____ faith. Would it be important to you/to them to observe any of the practices or rituals commonly used in that tradition as a person is dying/at the time of death (sacrament of the last rites/recite the Viddui (Jewish prayer of confession said before death) or Shema/read the 23rd Psalm/chant)?

Spiritual Assessment Goal #3:
To Ascertain Unmet Spiritual/Religious Needs and Determine Interest in Additional Spiritual Care

Questions to Assess Adequacy of Religious Support

- "Earlier you said you were raised in the _____ faith but had not practiced since you got married. Is this something that is important to you now? (Some people return to their religious upbringing as they face a life-threatening illness/their death. Others look to new or non-traditional sources of strength and meaning — nature, poetry, massage)

- "What is the effect of your illness on your religious beliefs and practices? Have your beliefs or practices changed since your illness? Is the support you are receiving from your religious community or clergy adequate? Can you talk with your spiritual leader openly about these decisions? About your fears, concerns, needs during this time?"

- "How can we assist you in drawing upon your faith/practice during this admission/while in our care?"

- "Your imam/priest/pastor/rabbi has visited you only once since you've been home. Is this customary in your tradition? Could he/she come more often if you wanted? Are there members of your faith community who could also help you sustain your religious practices?"

- "Although your own priest visits monthly to bring communion, does he spend time talking with you about your illness, your feelings?"

Questions to Determine Preferred Spiritual Care Providers and to Identify Interest in Chaplain

- "You have told me you find _____ (religious/spiritual practice) helpful. Would you like me to contact a clergy person from your own religious tradition to help you sustain this practice, meet this need? Shall I call our chaplain for you? Would you feel comfortable if the volunteer/nurse did _____ with you each morning, five times a day, etc.? Would you find it help if I _____ with you now or is this something you'd rather do in private, only with your family or members of your own faith community?"

- "While I know you have your own clergy person given how important your spirituality is in your life, I wonder if it would be helpful to have our chaplain/spiritual counselor also visit you? S/he knows a lot about your religious tradition. S/he has been very helpful to many persons in our care as they try to find hope, as they ask the kind of

questions you are asking now, in feeling like a whole person not just a sick body, in feeling less afraid about their own death/ after life, etc."

- "Every time I come, you express feelings of uselessness, seem afraid, cry out "why me"?, etc. We have a member of our team whose main area of training/expertise is in helping persons with these kinds of issues. You've made it very clear you are not "religious" so please understand that although this person's title is "chaplain" s/he is more like a counselor (is not out to convert you). S/He serves people from all walks of life, all faith and non-faiths, and will respect your values, beliefs, and philosophy/view of life. Shall I bring her/him with me next week, have her/him give you a call?"

Spiritual Assessment Goal #4:
To Uncover the Existence of Spiritual Suffering, Explore its Causes, and Develop a Plan of Care to Lessen or Alleviate It

Questions to Uncover the Existence of Spiritual Suffering

- "You said your greatest fear is that you will suffer. What would that look like? What do you mean by suffering? Are you suffering now?"
- "How has this illness affected you physically? Emotionally? Spiritually?"
- "Most people find that a serious illness affects their lives in many unexpected ways.
  What are some of the ways this illness has affected your life? What is hardest about being ill?"
- "Has being sick made any difference in what you believe/in how you view life/in how you see yourself/in your relationships with others?"

Questions to Learn About the Causes of Spiritual Suffering

- "Has your illness/prognosis/pain caused any confusion or doubts about your religious beliefs?" (To assess inadequacy of religious beliefs or spiritual development, conflict between religious teachings and experience, unanswered prayers)

- "Who or what do you blame for your illness? Do you have any feelings of anger, bitterness, resentment? Do you have any unresolved feelings about the life you've lived or unfinished business?" (To assess thoughts/feelings about divine punishment, guilt, unfairness, abandonment by God, self-blame, need for forgiveness or reconciliation)

- "What are you hoping for during this time? How will you feel if that hope is not fulfilled?" (To assess hopelessness/despair, hope/denial)

- "What do you miss most as a result of this illness? Now that you are no longer able to work/take care of your family/do _____ is there a reason or purpose to this time?" (To assess grief, loss of meaning and life purpose, loss of personhood)

- "Are you anxious or frightened? Do you have any fears or concerns about the future?" (To assess fear of the unknown, loss of control, fear of judgment, fear of after life, concern for family well-being)

Questions to Identify Means to Alleviate Spiritual Suffering

- "What has helped you cope with _____ in the past? What is your source of strength during your current illness? Is there anyone I should contact to help you explore this further, to help alleviate your fears, etc?"
- "Do you desire spiritual support to help you with these feelings or concerns?"
- "Are there any rituals or practices that would help you feel less alone/calm your anxiety?"

When to Refer to a Professional Spiritual Caregiver/Chaplain

- When a professional spiritual caregiver/chaplain is available:

    - Palliative care programs in most major hospitals should have access to their own specially trained spiritual care professional/chaplain and/or to the staff chaplains that serve the hospital at large
    - Hospice programs are even more likely to have a person filling the role of chaplain, though at times this need may be met through a network of volunteer community clergy
    - In spite of the increased request for attention to the spiritual dimension of people's lives and care in the medical setting, staffing with professionally trained spiritual care providers remains inadequate
    - Caseloads of chaplains often exceed their ability to do more than respond to crisis cases and/or to serve as a liaison to community religious resources
- When the time, training, or comfort level of the non-chaplain palliative care provider is not sufficient to meet the religious or spiritual needs of the patient and family: Ask yourself...
    - Do I have time to explore in further depth the impact of this person's religious beliefs upon their treatment decisions?
    - Do I know how to assess whether this patient's "pain" is physical or spiritual in origin?
    - Am I comfortable talking with this family about their religious beliefs and practices?
    - Am I likely to impose my own set of values or beliefs upon them in the process of assessing their needs?
    - Will I be comfortable in the face of strong emotions that may arise in the process of a more in-depth assessment of spiritual suffering?
    - Will I have the time and skills to provide comfort if my questions evoke great sadness or distress?
    - Who could best meet the needs of this patient and family at this time?
- When the dominant worldview or language of the patient and family is spiritual or religious
- When your brief assessment indicates:
    - Significant unmet spiritual or religious needs
    - Interest in spiritual care
    - The presence of spiritual suffering
    - Conflict between religious belief/practices and the medical plan of care
- When "bad news" has been delivered regarding
    - Terminal diagnosis
    - Failure of radiation or chemotherapy to halt the progress of the disease
    - When palliative care is introduced as a treatment option in lieu of curative therapies
- When difficult treatment decisions are to be implemented, such as:
    - Removal of life support
    - Starting "terminal sedation"
    - Cessation of artificial nutrition
    - Surgery that may result in radical changes in the patient's physical or cognitive status, or even end in death
- When the patient is actively dying

Potential Obstacles to Referral

There are several obstacles you may encounter in attempting to refer or "bridge" to the chaplain

- You may need to educate your patients and families about the person and role of the chaplain in order to get this team member "in the door"
- You may also need to use language that describes or explains the chaplain's role rather than use their official title

Addressing Common Misperceptions

- **Misperception #1:** The chaplain is Christian, only serves Christian patients, and will attempt to "convert" persons from other faith traditions
- **The Truth:**
    - Hospital and hospice chaplains are trained to serve persons from all religious traditions
    - Their job is to identify, respect, and integrate the patient's and family's own religious beliefs and practices into the medical plan of care, NOT to impose their own beliefs
    - In some settings, one may request a Jewish, Muslim, Catholic, or Protestant chaplain who does represent their own religious denomination

- **Misperception #2:** “I’m not religious, why would I want to see the chaplain?” In other words, the chaplain only provides religious or pastoral care. Many persons equate the chaplain with the only experience they have of religious leaders, a priest or rabbi
- **The Truth:** The chaplain’s area of expertise includes attention to the “spiritual” dimension of life which may include:
    - Questions of meaning, purpose and hope
    - Sources of comfort, relaxation, and strength
    - Ethical considerations
    - Core values that impact medical care
    - Grief and loss issues
    - The need for non-religious rituals of healing and closure, etc.

- **Misperception #3:** Chaplain visit = time of death. Contact with the chaplain means the patient is dying NOW. Calling or referring to the chaplain will somehow bring about the patient’s death
- **The Truth:** The chaplain is a person on the team who can:
    - Help sustain the person’s “spirit”
    - Help persons live as fully as possible
    - Help persons cope with the many challenges of being ill
    - Provide support to the family
    - Help persons draw upon their faith for strength, hope, and meaning during this difficult time

Strategies for Successful Referral

- **Referral Strategy #1:** Use your own rapport or trust with the patient and family:
    - “I know this chaplain well and have found her to be extremely helpful to other patients in my care”
- **Referral Strategy #2:** Offer to set up a meeting time or joint visit with the chaplain:
    - “May I invite her to our next appointment?”
    - “Is it ok if I bring her with me this afternoon on rounds?”
- **Referral Strategy #3:** Explain your reasons for suggesting the chaplain and/or indicate your level of concern for the patient/family well being
    - “Given how important your religious faith is to you, I think it would be helpful if we asked our chaplain to meet with you before you decide ____”
    - “I am really concerned about how much suffering you are in and want to be sure you see the person on our staff best equipped to help you. In my opinion that person is _____, our chaplain. S/he can help you much better than I with these important questions you are asking”
- **Referral Strategy #4:** Introduce the chaplain using a description of his or her role rather than the title, if you suspect resistance based upon common misperceptions
- **Referral Strategy #5:** Consult directly with the chaplain about the needs identified and request s/he stop by the room of the patient or call them directly at home. Address confidentiality issues with the patient and family ahead of time so they are prepared to have someone else contacting them who is aware of their condition and needs
    - "I will be making other members of our palliative care team aware of your admission into our program and aware you are considering palliative rather than curative treatment, so they can offer you their assistance directly."
    - "Our team members include our chaplain, our social worker, and others who will be stopping by to introduce themselves and their services.”

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