

PART III: SPIRITUAL PAIN/SPIRITUAL SUFFERING

- Spiritual pain/spiritual suffering: An overview
 - Cicely Saunders, founder of modern Hospice movement coined the phrase “total pain” to refer to physical, spiritual, emotional kinds of suffering commonly experienced by persons with life-limiting illness and their families
 - Joint Commission for Accreditation of Hospitals new pain standards represent a step forward, however, their focus is on physical pain only
 - Palliative care recognizes a complex relationship between physical pain (and other symptoms) and emotional and spiritual suffering
- Physical pain itself can be exacerbated by non-physical causes such as fear, anxiety, grief, unresolved guilt, depression, and unmet spiritual needs
 - Likewise, the inability to manage physical pain well can be due to emotional or spiritual issues
 - Persons may refuse pain medication due to fear or because they wish to be alert to interact with loved ones or because they believe they deserve to suffer
 - Unrelieved physical pain, among other symptoms, may itself cause emotional or spiritual suffering
 - Finally, some emotional or spiritual suffering — especially in certain cultures — may manifest itself as physical pain or other physical maladies
- Spiritual influences on physical pain
 - Spiritual frameworks and religious traditions influence how persons interpret and experience physical pain
 - How mind, body, and spirit are understood in relationship to each other and, in some cases, in relationship to a deity or deities is important to understand
 - Usually this framework is broader to include suffering of all kinds, whether its cause is physical or due to other causes
- Cultural interpretations of pain and suffering may conflict with goals of palliative care
 - Sometimes, these cultural and religious interpretations of pain and suffering can conflict with the stated goal of palliative care: to relieve pain and suffering
 - This is why a holistic, interdisciplinary assessment of pain is necessary
- Plans to manage pain pharmacologically often fail or patients do not comply with these plans when the larger spiritual framework is not adequately understood and integrated into the plan of care
- Spiritual practices may help in the management of physical pain
- Increasingly, medical staff recognize the palliative nature of religious and spiritual practices
- Some practices that have been proven to help in the management of physical pain include:
 - Prayer
 - Relaxation techniques
 - Chanting
 - Ritual cleansing
 - Acts of atonement
 - Shamanic treatments
 - Acupuncture
 - Herbal remedies
- Spiritual pain and suffering may be caused by physical pain and other symptoms
 - Loss of personhood
 - Despair
 - Feelings of abandonment by God
- Requests for assisted suicide (See Module 5: Physician Assisted Suicide Debate)
 - Assessment should include attention to spiritual suffering when pain is identified
 - Once the physical pain is better managed, the interdisciplinary team should explore whether there is any spiritual pain remaining
- Spiritual pain and suffering not caused by physical pain or other physical symptoms is common for persons with life-limiting illnesses and for their families
 - The knowledge that a person is dying may evoke:
 - Anger
 - Loss of hope and meaning
 - Shame or guilt
 - Grief

- Fear
 - A holistic pain assessment, therefore, should be conducted whether or not the person is manifesting any physical symptoms
- Signs of spiritual pain/suffering
 - Emotional
 - Restlessness/agitation/anxiety
 - Denial of illness or of reality of prognosis
 - Anger
 - Fear
 - Powerlessness and loss of control
 - Depression/flat affect
 - Dreams or nightmares
 - Behavioral
 - Refusal to take pain medication
 - Refusal of assistance with ADLs
 - Power struggles with caregivers or family
 - Puts self in unsafe care position
 - Frantically seeks advice from everyone
 - Active forms of self-harm
 - Loss of independence
 - Lack of engagement with activities that bring comfort or joy
 - Withdrawal/Isolation
 - Questions about “why” or duration of dying process
 - Statements about “not wanting to be a burden”
 - Metaphorical or symbolic language suggesting distress or unresolved concerns
 - If history of religious practice/affiliation, refuses religious leader or stops practice
 - Physical
 - Unrelieved pain
 - Shortness of breath
 - Sleeplessness
 - Other signs
 - Conflict between the goals of palliation and religious beliefs
 - Fixation on nutrition, herbal remedies, or miraculous cure
- The opportunity for spiritual growth at the end of life
 - Personal growth and healing often occur at the end of life
 - Although a terminal illness may be perceived or experienced primarily as negative or devastating, for many persons it becomes an opportunity for personal growth and healing
 - In its Greek origin, the word “crisis” includes a sense of possibility, connotes opportunity
 - Spiritual growth at end of life is possible for all persons regardless of belief
 - Persons need not share a religious or philosophical framework that says that good can come out of difficult times or life out of death in order to experience growth and healing at the end of life
 - Spiritual growth does not diminish suffering
 - Contrarily, that some healing happens does not diminish the very real suffering experienced both by the person who is terminally ill and by their family
- What precipitates personal and spiritual growth at the end of life?
 - As persons are less able to engage in life activities due to functional limitations, they have time for spiritual reflection and spiritual practice
 - Dependency, loss, fear, and suffering lead many persons to turn to (or return to) their religious tradition for meaning, strength, and comfort
 - Individual may take emotional and spiritual risks they would otherwise avoid
 - Because family members will not have another opportunity with their loved one, they often seek healing, connection, and reconciliation
 - Facing death evokes spiritual questions (about forgiveness, afterlife, the value of life itself) not normally asked in the course of daily living

- For medical staff opportunities for personal growth abound in our own feelings of powerlessness, experience of multiple losses or painful deaths and as we bear witness to the courage, love, and faith of patients and families
- How can the palliative care team help facilitate personal and spiritual growth for patients and families at the end of life?
 - By treating physical pain and other symptoms so patients and families have room to focus on relationships, life review, and spiritual practice
 - By offering assistance in finances and insurance matters and providing respite to limit caregiver stress
 - By helping the patient and family identify spiritual, relational, and emotional “goals” or “tasks” in addition to the management of physical pain
 - As an “outsider,” by noticing opportunities for healing and growth in the course of an illness that the patient and family might overlook
 - By asking whether their spiritual, philosophical, or religious framework offers comfort, meaning, or direction for action
 - By sharing stories of how other patients and families have found meaning, hope, and healing during this time of life
 - By being emotionally and spiritually “present” in the face of suffering and despair
 - By inviting the participation of the psychologist, social worker or chaplain

Assessment Tools and Opportunities

Visual Cues Indicating Possible Religious or Spiritual Beliefs and Practices

- Visual cues indicating possible religious or spiritual beliefs and practices may include:
 - Representations of religious figures or community leaders
 - Religious symbols or art
 - Prayer books or scripture
 - Books about the meaning of illness or healing practices
 - Religious clothing such as a prayer shawl
 - Altars or shrines
 - Herbal remedies
 - Any other objects considered sacred, invested with healing powers, or used for specific religious practices
- These items may be:
 - Found in a person's home
 - Brought to the hospital
 - In some cases, worn
- Special Note: It is always wise to explore what meaning these may hold for a patient or family rather than drawing direct assumptions about a person's religious orientation

Case Example: *As she was making morning rounds, the palliative care nurse noticed that Mrs. B. (who was unresponsive and actively dying) held something shiny in her left hand. The nurse easily identified the object as a rosary but was confused because Mrs. B. had clearly stated on her admission form that she had “no religious affiliation.” Later that day when Mrs. B's niece was visiting, the nurse asked if the rosary held special meaning for the patient. The niece burst into tears, confessing that the patient had left the Catholic Church many years ago and had never wanted to rejoin, even as she was dying. Upon further exploration, the niece confessed she was worried that if her aunt died outside of the church, they would never meet again in heaven. After expressing sympathy for her concern, the nurse asked the niece if it would be helpful for her to speak with the hospital's Catholic chaplain.*

Language As a Possible Indicator of Spiritual or Religious Framework

- As patients and families ask questions about their illness, discuss treatment plans, or carry on casual conversation, listen for phrases suggesting explicit religious beliefs such as:

“If God wills it...”
 “It is in the hands of the man upstairs.”
 “This medicine is a blessing.”
 “When she makes her transition...”

- Also pay attention for statements that speak to a more general philosophy about illness, fate, the value of life such as:

“You play the hand you are dealt”
 “He’s always been a fighter”
 “There are some things worse than death”

- As persons share pieces of their life story, their core values and perspectives are likely to emerge

Direct Questions from Patients and Families About Your Religious Beliefs

Note how, in both of the following case examples, the patients reveal important religious information about themselves, even though they appear to be asking about the religious beliefs of the staff person:

Case Example: *After attending rounds with the palliative care team, the fourth year medical student returned to the room of Mrs. Smith. Mrs. Smith recognized him from the earlier visit and asked: “I know the doctors have told me I only have a few days to live, but I believe God will send me a miracle. What do you believe?”*

Case Example: *As she was receiving her morning bath Mrs. Jones told the nursing assistant stories about her adult children and grand- children, promising to show the aide pictures when they returned to the room. She then asked directly: “Do you believe we really see our family members in heaven?”*

Language as a Possible Indicator of Spiritual Suffering

- Some commonly heard statements that may indicate spiritual suffering include:

“What’s the point of living like this?”
 “Why is God doing this to me?”
 “I just wish I were dead”
 “Can’t you do something?”
 “When she gets better...”

- Questions asked of the staff that seem to be purely medical may, in fact, be also indicate the existence of spiritual suffering
- For example, a family member asks “How much longer, doctor?” They may:
 - Be seeking factual information regarding prognosis
 - Need to know in order to plan for the patient’s care needs
 - Be doubting their own ability to cope emotionally, or
 - Perceive that the patient is experiencing prolonged suffering

Metaphorical or Symbolic Language as a Key to Unresolved Issues or Unmet Spiritual Needs

- Much has been written about the unique language of dying persons
- Cultures where it is customary to speak indirectly about sensitive topics often use coded words to talk about illness, dying, and the deceased
- Many ill persons, regardless of their cultural background will use language and images whose meaning should not to be taken literally
- In some cases, this language may refer to a set of religious beliefs or spiritual understanding of the world
 - For example, “I am ready to go home,” may indicate that the person wants to leave the hospital and die in their own house. It may also refer to heaven or paradise

Case Example: *An African-American Baptist woman with advanced lung cancer was admitted to the palliative care unit when it appeared she was actively dying. She was extremely agitated but due to her confusion could not tell the staff why. Mild sedation did not prove helpful. Periodically she would cry out using statements that made little sense to her family or caregivers. One day, she repeatedly said, “I’m*

dirty” and other phrases that suggested she needed bathing. After several bed baths and no end to the cries, the nurse consulted the patient’s chart and learned that she had a history of sexual abuse as well as unresolved fears about her salvation. The nurse contacted the chaplain who had provided the patient with pastoral counseling in her home. Following a “cleansing ritual” drawing upon the patient’s Christian belief in baptism as a means for the forgiveness of sin, the patient grew calm and died peacefully two days later.

Physical Symptoms That May Indicate the Existence of Spiritual Suffering or Unmet Spiritual Need

- Sometimes physical symptoms, including physical pain, are entirely physiological or organic in origin and should be treated pharmacologically
- However, many symptoms may also indicate the existence of untreated emotional or spiritual pain
- Untreated emotional or spiritual pain should be suspected in cases where symptoms include:
 - Physical pain that is unrelieved after extensive and appropriate pharmacological interventions
 - Pain that is unspecified or that frequently changes location
 - Anxiety
 - Increased shortness of breath
 - Restlessness or agitation
 - Fatigue
 - Flat affect or withdrawal
 - Insomnia

Case Example: *Mrs. Evans’ daughters reported to the hospice nurse that their mother was having extreme difficulty sleeping at night. She insisted on sitting up rather than lying down, would call out to them if they left the room, and refused to take either the roxynol or ativan that was prescribed to ease her respiratory distress and help her sleep. The nurse explored the patient’s resistance to the medications and possible reasons for her sleeplessness but received no clear explanation. Knowing the patient was a life-long Baptist who was not currently receiving any pastoral care, the nurse requested the chaplain visit. The chaplain discovered that the patient feared she would die if she closed her eyes. Upon further assessment, the chaplain learned that the patient believed she had committed an unforgivable “sin” that would keep her from going to heaven when she died.*

Behavioral Cues to Core Values and/or to Underlying Spiritual Suffering

- Declines assistance with personal hygiene and basic care needs
- Power struggles with family members or caregivers
- If history of practice/affiliation, refuses religious leader or stops religious practices
- Isolation, withdrawal from primary relationships
- Declines pain medication when physical pain present
- Lack of engagement in activities that bring comfort or joy (even when functionally able to do these)
- Family members continue to offer food by mouth even when informed of risk of aspiration

National Cancer Institute grant (R25 CA76449) to Sara J. Knight, Ph.D., at the Robert H. Lurie Comprehensive Cancer Center provided the funding for the development of this program.