

## PART IV: BASIC SKILLS AND TECHNIQUES IN PROVIDING SPIRITUAL CARE

### Assessment

- All team members are involved in spiritual assessment
  - All team members listen, utilize visual cues, and ask about patient and family spiritual/religious practices, frameworks, and needs
  - The chaplain or social worker often takes the lead
  - The chaplain or social worker customarily conduct an in-depth assessment at the start of care and develop a plan of spiritual care directed by patient and family goals
- Ongoing assessment is crucial
  - As the patient's health status changes
  - As new symptoms arise or are not relieved
  - If the dying process is prolonged
  - When death draws near
- Helpful assessment strategies include
  - Asking open-ended questions
    - "Is there anything you are hoping for during this time?"
    - "Where do you turn for strength?"
  - Providing options
    - "Some persons find that music, meditation, or prayer help relieve pain. Are any of these something you would find helpful?"

### Empathetic Presence

- What is empathetic presence?
  - "Don't do something. Just sit there!"
    - Health care professionals are experts at solving problems, identifying goals, measuring outcomes — that is, "fixing it" is our strength
    - The heart of spiritual care is empathetic presence, the opposite of fixing it
  - Empathetic presence helps people feel heard and not alone
    - When patients and families are experiencing losses, despair, questions about the meaning of suffering, or a sense of abandonment by the divine more than anything else they need to be heard and know they are not alone
    - It is essential to create an environment in which the person feels free to explore their concerns and openly express their feelings without feeling rejected or judged
  - Empathetic presence involves many skills and components
    - Active listening
    - Relaxed yet engaged body posture
    - Eye contact (when culturally appropriate)
    - Reassuring touch (when culturally appropriate)
    - Listening beyond or beneath the literal words said by a person to the deeper emotions, meaning, and needs
    - Empathetic presence may also involve a metaphorical "holding someone's pain" as you are open-hearted but do not become overwhelmed emotionally
    - It may also ask you to laugh, be joyous, and not focus on illness, pain, or dying
    - In the face of comments such as "why is God making me suffer so?" or "I just wish this were over, I can't stand it anymore" empathetic presence might include:
      - Acknowledging their suffering
      - Saying you are sorry you don't have the answer or solution
      - Providing reassurance of your (or the team's) ongoing care
  - What does empathetic presence do?
    - Empathetic presence is doing something

- Fear, anxiety, despair, and even physical pain frequently diminish with the person feels heard, understood, and accepted for where they are in the process of coming to terms or coping with their terminal illness
  - Empathetic presence:
    - Affirms personhood, self-worth, and dignity
    - Decreases isolation
    - Allows the person to find their own answers
    - (For religious persons) mediates divine care
- When empathetic presence is hard to sustain
  - In the face of unrelieved and prolonged suffering
  - When our own fears and insecurities are evoked
  - When we identify too strongly with the patient or family
  - Because of the age of the person
  - Because of how they remind us of our own family or previous losses
  - If we are the only team member involved in a case
  - When the patient or family are highly anxious and struggling with their own feelings of powerlessness
- An exercise in empathetic presence
  - Recall an experience from your own personal or professional life when you were unable to help someone feel better, take away their pain, or “fix” a problematic situation
    - How did you feel?
    - How did you cope with these feelings?
    - How did you respond to the person who was suffering?
  - Reflect for a moment:
    - Are you a problem solver, seeking solutions and offering advise?
    - What does it mean for you as a nurse, doctor, social worker, etc. to be powerless?
    - Do you feel a sense of failure in this situation?

### **Normalization of Patient/Family Experience**

- What is normalization?
  - Patients and families need to hear that what they are going through is “normal”
    - Although every person’s experience of illness, pain, spiritual suffering and dying/death is unique and needs to be validated as such
    - Patients and families also benefit from hearing they are not “crazy”
    - That is, their feelings, fears, and even disease progression are “normal”
  - Normalization builds trust
    - Normalization of the experience builds trust in the palliative care/hospice team
    - Conveys the message we have seen this before and know how to help
  - Normalization calms fears
    - Normalization can diminish anxiety and fear
    - Provides a “map” into this foreign territory
  - Normalization helps coping
    - It can sometimes help persons cope better with their own situation
    - Connects them with others who are going through or who have successfully gone through a similar time of trial
- Ways of normalizing experience
  - To illustrate by example: A patient is highly anxious about their future ability to cope with symptoms and with the task of saying goodbye to loved ones
    - Method one: One strategy of normalization would be to respond by saying
      - “Of course you are anxious”
      - “It makes sense to me”
      - “After all, you’ve never gone through this before and it is a lot to take on at once”
    - Method two: Another strategy would be to
      - Tell the person that many of your patients were also anxious at first

- But, with a little assistance, these persons grew more trusting in how they would cope with the future
- When normalization can be helpful
  - When patient or family express wishes to hasten the dying process
    - Frees persons to talk more about their underlying reasons or feelings by reducing judgment and guilt
  - When the patient is actively dying
    - Relieves concerns about terminal agitation, lack of appetite, inability to swallow, visions of deceased loved ones, and their own feelings of powerlessness and grief
- Use of religion in normalization
  - Examples drawn from the specific religious literature or faith community of patients and families can help normalize and validate spiritual experiences
  - The example may help:
    - Affirm their strength to cope
    - Free them from having to be perfect
    - Sustain their connection with something beyond themselves (e.g., human community, tradition, the divine)
- Appropriate vs. inappropriate use of normalization: Please exercise great care in using this technique
  - If used at the wrong time or in the wrong way persons may feel you are disregarding their feelings or trying to minimize their suffering
  - How you use it makes all the difference

### **Life Review**

- Life review helps persons with concerns about:
  - The purpose of their life
  - Self-worth
  - Need for forgiveness
  - Closure with the past
  - The progressive losses that accompany a life-limiting illness
- Life review can help establish a “legacy”
  - As a formal exercise, it can establish a person’s “legacy”
    - How they will live on in the future or how they wish to be remembered
    - In this way, it can also be helpful to bereaved families as it gives them a tangible “piece” of the deceased loved one
- Life review can have special religious or spiritual significance
  - For spiritual or religious persons, life review pays attention to their:
    - Role in a community of faith
    - Religious identity or self-understanding
    - Relationship with the divine
  - For spiritual or religious persons life review can also be a useful tool:
    - To increase a sense of trust in the future (if God has seen them through hard times in the past)
    - For spiritual growth work
    - To resolve fears about the afterlife

### **Exploration of Sources of Hope & Meaning**

- Guidelines for exploring meaning
  - A larger framework of meaning can give patients and families a sense of purpose and ease suffering
  - It is preferable for the patient or family to uncover and identify their own meaning rather than have this offered to them by others
  - Religious or spiritual explanations for suffering, loss, and life-limiting disease are complex and often may not be comforting
    - Take care when exploring these issues with persons
    - Follow rather than initiate and avoid intellectual debate

- Guidelines for exploring hope
  - Sustaining hope in a cure or divine miracle, even if it seems unfounded, may be necessary for some persons
    - Refocusing on short term, achievable goals, when the patient and family are ready to do so, can defend against despair and help give a sense of purpose and control
    - Ask persons what they are hoping for during this time
    - If they indicate they have no hope, allow for expression of these feelings
    - It may then be helpful to offer them other things to hope for such as:
      - Comfort
      - Strength for their family
      - To be well-remembered
      - To see the birth of a grandchild, etc.

### **Affirmation of Sources of Strength & Comfort**

- Ask questions to assess sources of strength and comfort
  - “How have you coped with difficult times in the past?”
  - “Where did you find strength?”
  - “What gives you comfort?”
  - “Is there anything you would find comforting now?”
- Provide a “laundry list” if persons fail to come up with their own sources of strength and comfort:
  - “Some persons turn to their family, their clergy, scripture, or humor for strength”
  - “Have you ever tried massage, meditation, soothing music, prayer, a walk in the woods, being held or a good cry?”
- Explicitly name and affirm the qualities you observe as you work with patients and their families:
  - Wisdom
  - Knowledge
  - Life experience
  - Decision-making power
  - Adaptability
  - Graceful way of dealing with change or conflict
  - Open communication
  - Denial
  - Particular philosophy of life

### **Reframing**

- What is reframing?
  - At times, patients and families may benefit from seeing things from a different perspective
  - Reframing a situation can help persons cope, find meaning, and hope
  - A gentle way to introduce a different, more positive perspective is to begin with the words
    - “I wonder whether you have at times thought of this experience in different ways”
    - Or, draw upon examples or stories of other patients and families to open up the possibility of a different meaning or outcome
- Situations where reframing is helpful
  - Palliative care and hospice professionals frequently use this technique as we explain our medical care:
    - “Although your doctor has told you nothing more can be done for your cancer, please rest assured there is a lot we can do to help you and your family during this difficult time.”
  - Other areas that are commonly reframed by palliative care and hospice include:
    - Who needs to be present at the time of death
    - The impact of a death on family members
    - Role changes
  - Reframing and spiritual care
    - In spiritual care, reframing draws upon the person’s own belief system and religious tradition
    - At times it includes educating persons about aspects of their own tradition that may not occur to them or be unknown to them

## **Diversional & Life-Affirming Activities**

- One of the most powerful ways to promote spiritual well-being is to connect persons with sources of life and joy, even in the midst of illness, suffering, and death
- The laugh of a child, a sunny day, the love of family, a political victory, even an exciting sports event can expand the world of ill persons and of their families
- Sometimes just taking the mind away from a problem, even for a short while, can be restorative
- As persons with terminal illness are able to “do” less and less, enjoying the simple pleasures of life may help restore a sense of purpose and personhood
- For spiritual or religious persons, this may help reconnect them with that which is sacred, divine, or transcendent and reestablish a sense of gratitude and peace

## **Prayer, Rituals & Observance of Religious Practices**

- Sustaining religious practices
  - Knowing, respecting, and helping **sustain** a person’s religious rituals and practices is the responsibility of all team members
- Encouraging religious practices
- The degree to which you as a team member **encourage** the patient and family to utilize their spiritual or religious practices to find meaning, strength, and comfort depends on:
  - Your knowledge of their spirituality
  - Their comfort level in sharing this with you
- Use open ended questions or suggestions:
  - “Is there anything from your spiritual practice that would be helpful to do now?” (Before a difficult medical decision or at the time of death, for example)
  - “In the past you have told me that prayer helps your pain. While we wait for the morphine to take effect, do you think it would help you to pray or would you rather sit quietly?”
- Participating in religious practices
  - The degree to which you as a team member **participate** in the spiritual or religious practices of patients and families depends on both their and your own comfort level
  - Generally, it is best to let patients and families initiate the request for your participation
  - If you are unclear as to whether your presence is wanted, ask
  - If you are uncomfortable with a request made of you to participate, let them know in ways that show your respect for their beliefs and needs in this area while acknowledging your own boundaries

## **Guidelines for Spiritual Care by Non-Chaplain Health Care Professionals**

- Listen more than talk
  - Encourage patient and family to give voice, tell stories
  - Explore but don’t probe
  - Help persons feel “heard”
- Practice being present
  - It is ok to say, “ I don’t know, but I’m here, I hear you are in pain”
  - Monitor your own need to do something or fix it
- Avoid judgment of beliefs, practices, or emotional responses
- Refrain from proselytizing or imposing your own beliefs
  - Be aware of your own beliefs and biases
  - Be careful: Even if you share the same religious tradition, beliefs and practices vary widely
- Avoid discussion of religious doctrine, dogma, and complicated theological questions
  - Usually the person is not needing an intellectual or theoretical explanation
  - Usually the person needs comfort and reassurance
- Avoid religious clichés
  - Such as “It is God’s will” or “God never gives you more than you can bear”
  - These are not usually very comforting unless they have been voiced consistently by the patient and family themselves
- Respect patient and family spiritual framework and practices

- Provide care in keeping with them
- Respect patient and family privacy in this area
- Let the patient and family invite you to participate in their religious observances or practices rather than you initiating prayer, ritual, scripture reading, etc.
- Coordinate and collaborate as a member of the interdisciplinary team
  - Follow the plan for spiritual care agreed upon by patient, family, and the team

### **The Role of the Chaplain in End of Life Care**

- The chaplain's training
  - Master's level preparation
    - Pastoral and family counseling
    - World religious traditions, ritual, and theology
  - Residency or internship in Clinical Pastoral Education (CPE)
  - This additional training ensures knowledge of:
    - Medical procedures and processes
    - Spiritual concerns that arise in the face of illness
    - Attention to cultural and religious diversity
    - Theological perspectives on health, disease, dying, and death
  - CPE also builds skills in:
    - Assessment of spiritual distress
    - The chaplain's role in the interdisciplinary team
    - Awareness of one's own spiritual and emotional biases
  - Perhaps more than any other discipline in the health care setting, chaplains receive intensive preparation to help patients, families, and other staff deal with issues of loss, death, and dying
- Chaplain's role vis-à-vis clergy
  - Broader role than that of a clergy person who represents his or her own faith tradition
  - While in some institutions patients may request a Muslim, Jewish, Protestant, or Roman Catholic chaplain, by and large chaplains serve persons from all religious traditions
  - Chaplains attend to specific religious needs such as:
    - Ensuring that medical professionals respect religious beliefs and prohibitions
      - Officiating at services in the hospital for religious holidays
      - Offering prayers
    - Chaplains often work alongside the patient and family's own clergy, serving as a "translator" and patient/family advocate within a complex and often confusing medical environment
    - Though clergy are increasingly well-prepared to deal with end-of-life issues, many remain uncomfortable or unknowledgeable in this area
    - Unlike most clergy, chaplains also provide spiritual (non-religious) care and counseling to patients and their families who are not affiliated with any specific religious tradition
- Chaplain's role in ethical matters
  - Because of their understanding of medical issues and expertise in helping patients and families identify their values and beliefs, chaplains are often called upon to assist with challenging medical decisions
  - Many chaplains are members of the hospital's ethics committee and have received specialized training in ethical decisions at the end-of-life
- The chaplain wears many hats
  - The role of the chaplain is exceedingly ambiguous and flexible
  - It is defined as much by the expectations of patients, families, and other health care providers as it is by the self-understanding of each chaplain
  - This role is often narrowed to a mere provider of sacraments or religious ritual
  - Education may be necessary so that patients and families receive all that the chaplain has to offer
  - At its richest, the role of the chaplain may include:
    - Educator about religious and cultural frameworks and practices
    - Translator and bridge-builder between the "culture" of medicine and that of patients/families

- Facilitator of communication
  - Advocate for patient and family beliefs, religious and spiritual needs
  - Mediator of the sacred, transcendent, divine
  - Counselor, healer, agent of hope
  - Ritual expert
  - Calming presence in the face of crises
  - Liaison to community clergy
- Chaplain's role in providing spiritual care to staff
    - Chaplains who are on staff at hospitals and those who are members of a hospice or palliative care team provide both formal and informal spiritual and grief counseling to other health care providers
    - In this role, they may:
      - Plan and officiate at memorial services
      - Facilitate de-briefing sessions directed at the needs of other staff
      - Make themselves available to help staff with questions about:
        - Meaning
        - Hope
        - Power/powerlessness
        - Ethical conflicts
        - Understanding of the divine
        - The afterlife
        - Other spiritual concerns that may arise in the course of providing care to terminally ill persons and their families

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