

PART II: COMMON NEEDS AND GOALS

Finding Hope. Hope is a Fragile Thing

- At one and the same time, a patient or family member may accept the news that no curative treatment remains yet still proclaim that they will “beat this”
- Coming to terms with their prognosis is a process
- The palliative care team can help patients and families identify other objects of hope

Assessing Hope

- To assess a patient’s or family’s sense of hope, you might ask, “Are there other things you are hoping for during this time?”
- Some suggestions you might offer include:
 - Hope to not be in pain
 - Hope to be treated with dignity
 - Hope that their family will be ok
 - Hope to be remembered well
 - Hope they won’t be abandoned
 - Hope to go to Las Vegas one last time
 - Hope to see their son graduate from college
 - Hope to find peace
- Hoping for Death: Be aware that for some religious persons hope may lie in:
 - Being forgiven by God
 - The promise of life after death (heaven or reincarnation)
 - Reunion with deceased loved ones
- Temporary despair or hopelessness is a common and understandable response to finding out that one is terminally ill, that no curative treatment remains
 - Persons need time to grieve the many losses that accompany this prognosis
 - Moving on to other objects of hope too quickly may short-circuit this process
 - Some religious persons may feel as if God has not answered their prayer or even abandoned them when news of terminal diagnosis is received--This may cause a crisis in their faith
 - A referral to a chaplain may be appropriate at this time
- Belief in a miracle cure
 - Perhaps most challenging to medical professionals is when a patient or family member accepts the news that the doctors have run out of curative measures, accepts palliative care or hospice
 - Yet holds firm to the belief in a miraculous (divine) cure
 - **Case Study:** *A young resident who had been on rounds with the palliative care team returned to the room of Mrs. S. for follow up. As he was getting ready to leave, she said to him: “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 think?” Consider, what does this woman really need to hear? Statistics? The “truth” that she is dying? Perhaps she needs to have her faith affirmed as a significant part of her life, as a resource for coping with the news, as a place of hope in the face of despair? Perhaps she can hear both perspectives — the medical and religious — and prepare for both eventualities?*
- Hoping for death is normal
 - Sometimes, the only hope is that there will be an end
 - An end to suffering
 - An end to what is experienced or perceived as a pointless existence
 - An end to life itself
 - Many persons feel as if they are weak or that it is unacceptable to wish they were dead; yet it is a common experience for persons with life-threatening illness

Health Care Professionals Can Do Many Things to Help Those Who Hope for Death

- Normalizing the wish for death

- Confirming that a person is indeed growing weaker or that they have multiple symptoms that indicate that death is near
- Merely stating that you know this will not go on forever

The Search for Meaning. The Question of Why.

- Questioning is common at the end of life
- Many forms of suffering may accompany a life threatening illness:
 - Physical pain
 - The loss of independence
 - Watching a loved one decline and feeling powerless to change the course of the illness
- This suffering leads many persons to question “why”?
 - Why is this happening to me?
 - Why my loved one?
 - Why now when we’ve just retired?
 - Is there a reason or purpose for this life-altering event?
- Spiritual and religious frameworks can provide meaning in the midst of suffering
- Suffering can be made bearable, and maybe even transformed into an opportunity for personal growth and healing, with the aid of such frameworks of meaning

Case Study

Mrs. Allen’s lung cancer progressed very slowly. Though her respiratory symptoms and pain were well controlled, she suffered considerably from being unable to care for her own bodily functions, manage her own household, and remain active in her church. Initially, Mrs. Allen was able to cope with these losses and remain in good spirits by believing that her daughters needed this time to “prepare” for her death. For a while, she found meaning in the belief that God was helping her grow spiritually in and through this state of dependence. As the months wore on, however, and these reasons for being alive were fulfilled, Mrs. Allen despaired. She prayed for God to take her. With the help of the hospice team, she found renewed strength and peace by affirming her long-standing belief that “God has a plan and purpose for everything, even if He doesn’t tell us what it is.” To remain faithful was the answer to her quest for meaning.

What Can Be Done to Help Those Who are Suffering and Questioning

- Let patients and families feel heard
 - Patients and families need permission to express their sense that there is no point or meaning
 - As with the loss of hope, good spiritual care by the palliative care team allows for these feelings to be heard
- Respond to expressions of self-blame or anger at God
 - Often, unrelieved suffering leads persons to blame themselves or God
 - “I must have done something to deserve this kind of life.”
 - Normalizing these feelings and reviewing with the person their life history may bring some release from blame, even as it may leave the person with no good explanation for their suffering
 - If self-blame or anger at God persists, the chaplain or counselor should be notified
- Take cues from the patient and family
- It is not appropriate to impose your own explanations or reasons
- It is better to explore, probe, and even offer some ideas drawn from the life history of the patient or from observations of family dynamics

Sense of Purpose and Identity

- A life-threatening illness can challenge sense of purpose and identity
 - The search for meaning and purpose by persons facing a life-threatening illness may also express itself through questions such as:
 - Who am I now?
 - What good am I?
 - What purpose does my existence serve?

- Who am I now that I can no longer work, provide for my family, teach, cook for my spouse, take care of others, be a cantor in my temple, garden, socialize with friends?
- Mourning, affirming, and redefining purpose and identity can help in the search for meaning
- It is appropriate and important to mourn parts of one's life and identity that are indeed taken away with the progression of disease
- Equally important is affirming a sense of continuity with who one has been in the past
- It might also be appropriate to help persons redefine their current purpose and identity
- When Meaning and Purpose Can't Be Found
 - When no meaning or purpose is to be found, relief can sometimes come through "distraction therapy"
 - "You are still here: Can we see if there is something you can do to get your mind off of just waiting to die?"

Sustaining Personhood and Community

Sustaining Personhood

- Personhood is defined by society and may be threatened by illness
 - In Western society, personhood is largely defined as:
 - Being a subject with say over one's body, emotions, decisions, and life goals
 - A set of character traits, a defining life story, or identity that makes it possible to say "I am John W. and not James X"
 - For many, it includes one's role or relationships in a family or community
 - In the face of multiple losses and increased dependence on others for basic needs, those who are terminally ill may feel as if they are not the same person
 - Sometimes they feel as if they are not a person at all, but just a sick body
- Spiritual care helps sustain personhood
 - Spiritual care aims to sustain one's sense of being a person with value, dignity, and worth
 - These simple but often overlooked strategies may be employed by all members of the palliative care and hospice team to help sustain a sense of personhood:
 - Talk to the ill person rather than about them in their presence, even if they are not capable of complete understanding
 - Ask persons how they are doing or feeling before focusing on specific medical problems
 - Explore what it is that helps that person feel like a human being rather than just a "case" or "patient"
 - Acknowledge that this person is someone's daughter or son, mother or brother
 - Offer choices and help persons identify areas where they can have some say to compensate for the tremendous loss of control and independence that accompanies a progressive terminal illness
- Severe threats to personhood
 - In rare instances, a person's identity can be so completely defined by one value, goal, or characteristic that the loss of this threatens to dissolve their personhood entirely
 - For some, the very essence of who they are would be lost if their disease led to a state of dependence on others and loss of bodily and mental functioning
 - Occasionally, this threat to identity may motivate requests for actions such as physician assisted suicide and terminal sedation (see Module 5: Assisted Suicide Debate)
- Diseases affecting mental capacity
 - With diseases that affect mental capacity such as Alzheimer's, brain tumors, or metastases to the brain, loss of personhood is a particularly painful reality for family members caring for their loved one
 - At the same time as a family is mourning the progressive loss of the person they knew, they may need to act as if they are the same person
 - Affirming the life story and contributions of the terminally ill person as well as naming the place that person has in the life of those present is one way to help sustain the sense of personhood

Case Study

Mr. and Mrs. M. had been married 50 years when Mrs. M. was diagnosed with end stage glioblastoma. As the disease progressed, she no longer spoke, made no meaningful eye contact or gestures, did not respond to even simple commands, and showed no sign of recognizing the voice or presence of her husband. Mr. M. would periodically despair and ask members of the hospice team if they could do something to end this. "She's gone, she's not here anymore. What's the point?"

On other days, he would persist, however, in telling her about his day, caressing her arms, and advocating for respectful treatment of her by the nurses and aids who came to the home. "She's not a piece of meat, you know. She's a human being. She's still my wife." As time went on, he came to believe that somehow she knew he was there, that the bond of love they shared was deeper than the mind could grasp, and that his presence and love for her was making a difference, even if it couldn't change the course of the disease.

Sustaining Community

- Sustaining a sense of community is important during the dying process
 - Sustaining a dying person's sense of community is an important spiritual need even as those social roles and bonds are being changed, if not ended, by death
 - Community may involve a sense of connection with any or all of the following:
 - Family
 - Friends
 - Work place
 - School
 - Local organizations
 - Faith community
 - A divine being
- Roles within these various communities will inevitably change as the person's health declines
 - Persons may need to explore what it means to go from one role to another
 - Caregiver to the person being taken care of by others
 - Church leader to congregant receiving pastoral care
 - Persons may also need to mourn the loss these transitions entail
 - Sometimes it is possible to affirm continued role as mother, provider, teacher, minister, caregiver by redefining what that means under these new circumstances
- All members of the end of life care team can encourage and facilitate ongoing involvement between patient and community
 - Educating members of these communities both about the importance of their presence
 - Educating community members about how to interact in meaningful, helpful ways with the terminally ill person
 - Requesting the involvement of faith communities if this is desired by the patient and family
- Members of faith communities can help patients and families in many ways at end of life (See More About Clergy and Faith Communities)
 - Coming to the residence of the person who is ill
 - Helping with transportation to services
 - Providing practical assistance such as:
 - Respite for the caregivers
 - Meals
 - Running errands
 - By remaining involved in the life of the persons as they face their illness and death, members of faith communities may help:
 - Affirm the value of the person
 - Give hope that their family will not be alone
 - Mediate a sense of divine presence

Coping with Change and Uncertainty

Change and Uncertainty: The Challenge

- Change and uncertainty are inevitable at the end of life

- Many persons with life-limiting diseases and their family members describe this time as “being on a rollercoaster” or venturing into “unknown territory”
- Though the ultimate outcome (death) may be clear and accepted by all, the days and months in between are filled with uncertainty
- Change in functioning at the end of life is unpredictable
 - One day a person may feel relatively good, the next day any number of symptoms may appear without forewarning
 - How the ill person or their family will respond emotionally to the many changes that are to come is unpredictable
 - Even when physicians are willing and able to provide a prognosis, no one knows the precise timing of this particular dying process
 - Fear, anxiety, and feelings of powerlessness are nearly universal

Change and Uncertainty: What Health Care Professionals Can Do

- Listen and normalize fears
 - Provide an opportunity for persons to talk about the source of their anxiety or fear
 - “Being heard” in and of itself can sometimes lessen the spiritual distress
- Help identify sources of comfort and order
 - Helping persons identify something that is solid, trustworthy, or that provides a sense of order and direction is another useful strategy
 - Sources of comfort and order may include...
 - Other people
 - This may be a family member they can count on
 - It may also be the palliative care team with their knowledge of what the dying process usually looks like physically, what the customary emotional responses to change are both for the patient and family, and what practical care needs may arise as the disease progresses
 - Spiritual and religious traditions
 - These frameworks are often a source of comfort in the face of such uncertainty
 - From secular spiritual practices such as “take it one day at a time” to religious beliefs in a divine being who has predetermined the timing of one’s death, such frameworks help persons cope with what is not in their control
 - Ritual is another useful resource for reestablishing a sense of order
 - Rituals need not be elaborate, precisely defined spiritual practices
 - Include ordinary habits
 - Bathing at the same time every day
 - Saying goodnight to a spouse with the same words each evening
 - When a nurse or volunteer keep regularly scheduled appointment times, this can help establish order
 - For adherents of religious traditions, maintaining proscribed rituals will be especially important, albeit challenging
 - Some creativity might be needed to adapt these rituals to meet the physical or cognitive limitations of the person who is ill

Taking Care of Unfinished Business and the Need for Forgiveness

Facilitating Life Review

- Life review is a natural part of the end of life
- As persons face their own death, they naturally ask questions such as:
 - “Was my life well-lived?”
 - “How will I be remembered?”
- The process of reviewing one’s life provides the opportunity to affirm the unique contributions and value of the person who is dying
- Physicians, nurses, nursing assistants, volunteers, occupational therapists, and counselors have many opportunities to assist in this developmental task

- Asking the person to share a piece of their story or what they are most proud of are simple ways to begin
- You may also encourage family members and friends to identify what they have learned from the dying person or how that person has made a difference to them

Attending to Unfinished Business

- Coming to terms with one's past is an important task at the end of life
- The end of life represents a chance for persons to resolve or come to terms with their mistakes, failures, regrets, and unfinished business
- How the dying person or family feels about or perceives their past matters far more than the judgment or perception of anyone else
- Religious and spiritual frameworks play a role in this process
 - Framework from which to assess life
 - Means to "make right" or be released from sins or failures
- The end of life care team also plays an important role in this process
 - All members of the interdisciplinary team may be called upon to help persons gain a sense of peace with the life they have lived, when that is the goal (explicit or implicit) of the dying person and their family
 - However, when strong negative or judgmental feelings about a person's past arise, members of the team with professional expertise in this area should be brought in if possible
 - Social workers, chaplains, and psychologists can:
 - Use life review, confession, and reframing techniques in addition to an accepting, non-judgmental presence
 - Facilitate communication between the dying person and family/friends as needed to bring closure and reconciliation
 - Encourage the dying person to take specific actions to make amends for their past actions or complete an unfinished task to attain the peace they desire
 - Words of forgiveness and rituals of reconciliation may occur with the assistance of a professional spiritual caregiver or member of the clergy
- Unresolved past issues may manifest themselves in physical or psychological symptoms
 - Agitation
 - Restlessness
 - Sleeplessness
 - Pain that is not lessened with appropriate medications
 - Resistance to taking pain medication
 - Even shortness of breath or panic should be regarded as possible indications of spiritual distress
- Unresolved issues from the past or a need for forgiveness may also cause psychological or emotional symptoms such as:
 - Fear of dying
 - Concerns about salvation or the after life, and
 - General despair

Fear of Death, Questions About Life After Death & Spiritual Care at the Time of Death

Fear of Death

- Fears about death itself and the dying process are common at the end of life
 - It is important to assess whether the person's fear is about **death itself** or about the **dying process**
 - Common fears about the **dying process** include:
 - Fear of being in pain
 - Fear of suffocating
 - Fear of losing control of bodily functions
 - Fear of loss of mental functioning
 - Fear of **death itself** — of the cessation of life or transition to the next life, depending on the spiritual and cultural framework of the patient — may also have various causes
 - The unknown aspects of this event

- Separation from loved ones
- What awaits them in their next life

The Interdisciplinary Team Together Can Lessen These Fears with Education and Practical Assistance

Questions about life after death - Avoid imposing your own beliefs

- As members of the palliative care team respond to fears about death, there is a great risk of imposing our own beliefs
- Patients and families are likely to ask such questions as
 - “What do you believe about the after-life?”
 - “Do you really think I’ll see my uncle John (deceased) when I get to heaven?”
- Remember
 - Dying person and family are not often asking what YOU believe
 - They may be trying to clarify their own beliefs and find reassurance and hope
- Be aware of commonly imposed beliefs...
 - If patients call upon the name of deceased loved ones or report “seeing” these persons in the room, many palliative care professionals unwittingly impose a spiritual framework upon this experience by suggesting that the spirits of the deceased are coming to the dying person to help them with the transition
 - Likewise, when a person’s dying is prolonged, we may look for “spiritual” explanations — “God isn’t ready for her yet” or “she must have some unfinished business here on earth” — that may or may not be in keeping with the spiritual framework and beliefs of the patient and family
 - A good death requires that a person be at peace
 - A good death requires that a person and their family accept what is happening, i.e., not be in denial
 - No one should die in pain
 - Reconciliation within a family is a shared value/goal of all patients
 - Family members should say goodbye and/or give the dying person permission to go
 - Death occurs at the moment breathing (or heart beat) stops
- Use strategies that help patient and family explore and clarify their own beliefs
 - Putting the question back to them is a useful strategy:
 - “What have you been taught through your own tradition about the after-life?”
 - “Do you have any images or ideas about what it might be like?”
 - “What would you like for the after life to look like?”
 - “It sounds important to you that you connect up with family again in heaven. Would it be comforting to see your Uncle John again?”
 - Helping the patient and family to explore their own beliefs and clarifying what it is they are asking/in need of spiritually and emotionally at the time of death and in regards to life after death should be the role of all team members
 - Offering a list of possible explanations or a number of opposing beliefs provides some direction when persons are feeling confused about what they believe or want to do

Spiritual Care at the Time of Death

- Defining death
 - Different religious and cultural traditions offer various definitions for “death” and “dead”
- Important factors at the time of death. There are several factors at the time of death that are believed to impact spiritual life after death, depending on the religious and cultural framework
 - How a person dies
 - For some religions and cultures, how a person dies — violently, peacefully, by their own hand or at the hands of another — directly relates to the quality and kind of existence the person has in the after life or the next life
 - Emotional and spiritual state as death approaches
 - The state of the dying person’s emotional and spiritual well-being as death approaches (peaceful/agitated, doubtful/trusting, alert/sedated, attached/released) is believed by some to impact their transition and life after this one

- Care provided to the dying person
 - The spiritual and medical care provided by others to the dying person and what persons do for the soul and body of the deceased is also held to affect the spiritual life after (chanting, prayers for the soul in purgatory, how the remains are handled, ritual cleansing of the body, the emotional state of the bereaved)
- Customs and rituals after death
 - Funeral and burial customs as well as mourning rituals that may last for months to years not only are believed to impact the spiritual existence of the deceased but serve the needs of the bereaved as well
- Bonds Between the Dead and the Living
 - Beliefs about bonds between the dead and the living vary across cultures
 - Just as there are differences in how death and life after death are conceptualized by the various religions and cultures so there are vast differences in how persons understand the bonds between the deceased and the living
 - How these relationships are understood directly affects the process of grieving and the provision of bereavement care
 - These beliefs can have important implications for grief and bereavement
- Understanding and respecting these beliefs is essential for good palliative care
 - Asking persons how they think about these relationships is key to providing appropriate and helpful spiritual care
 - It is essential to learn about these spiritual frameworks both to bring comfort and meaning and to avoid violating (potentially soul-threatening) prohibitions

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