This course was developed in 2004 with many revisions since then; Drs. Drew Rosielle and Kathryn Neuendorf were important contributors to past editions.
Disclaimer

While this program provides educational information, this information is not medical advice. Health care providers should exercise their own independent clinical judgment. Some of the information cites the use of a product in a dosage, for an indication, or in a manner other than that recommended in the product labeling.

Accordingly, the official prescribing information should be consulted before any such product is used.
Objectives

- Identify eight domains of a comprehensive psychosocial assessment.
- Review two common patient coping mechanisms.
- Review the meaning of a terminal illness in terms of losses.
- Identify three different types of grief.
- Learn three tasks of the physician in providing psychosocial and spiritual care.
Case Question

- You have been caring for a 63 yo male diagnosed with ALS one year ago. He lost the ability to walk 6 months ago. Currently, he is in the hospital with aspiration pneumonia. When you come in to assess the patient today, he asks you, “Why is God punishing me like this? What did I do to deserve this disease?”

How do you respond?
The term psychosocial refers to the mind’s ability to, consciously or unconsciously, adjust and relate the body to its social environment.\(^1\)
- It relates social conditions to mental health/psychological aspects.

A psychosocial assessment is the task of the entire care team, *including the physician*.
- Although a need may be identified by the physician, other team members, such as psychologists, chaplains, social workers, etc. may be the ones to address that need with the patient.
Psychosocial assessment

Before starting a psychosocial assessment, the physician should:
- Establish an atmosphere of trust
- Sit down, build relationship
- Make sure that the patient is not in physical discomfort

Express interest by asking specific questions
- Patients generally respond favorably
- Direct questions about psychological and spiritual health lets the patient know that it is valid to have these concerns and important to talk about them.
Psychosocial assessment

- Patient-Physician relationship
- Meaning of illness
- Psychiatric vulnerabilities
- Sense of Self

- Personal Relationships
- Spirituality
- Financial Concerns
- Coping style

Patient-Physician Relationship

- To allow patient’s to share their thoughts on psychosocial concerns, the patient-physician relationship should have
  - Trust
  - Good Communication
- Potential Questions to ask
  - *How are we doing together?*
  - *Are there ways in which I could be more helpful to you?*
  - *Is there anything you would like to change in how we work together?*
Meaning of Illness

- Patients may feel that they were specifically chosen by a higher power to have an illness or may feel they are to blame for their illness
  - It is often crucial to understand these beliefs to be able to talk to the patient about care.
  - A patient who thinks that suffering with pain is God’s way of testing her faith may not want the pain to be treated;
  - A patient who thinks he could have avoided pancreatic cancer if he didn’t drink so much may not accept help from others.
Meaning of Illness

• Not every patient attaches meaning to his/her illness.

• If you suspect that your patient is facing this challenge, potential questions to ask:
  • Does your illness have an underlying meaning for you?
  • Do you think you did something to cause your illness?
  • Do you view your illness as a punishment?
Psychiatric vulnerabilities

• It is thought that patients with prior psychiatric diagnoses are at a greater risk for psychiatric decompensation when facing a serious illness
  • No studies exist to support this theory
  • Depression and anxiety are seen commonly in terminal illness
  • PTSD, personality disorders and substance abuse can complicate matters in the care of the patient
  • (addressed further in modules on Depression and Addiction Assessment)
Psychiatric vulnerabilities

Potential Questions to ask

- Have you ever had trouble with depression? Do you feel depressed now?
- Have you ever used alcohol or drugs to help you cope with difficult times?
- Have you ever sought treatment for emotional difficulties?
Sense of Self

- Cascade of losses (slide 31&32) can challenge the patient’s “role” in life
- Sense of independence and control is difficult to maintain at times of illness
- Patients want to maintain dignity
Sense of Self

Potential questions to ask

- How can we best honor who you are and what is important to you as we take care of you?
- Has your illness changed your sense of self-worth?
- Have you taken on a new role in your family since getting your diagnosis? If so, has that been difficult?
Personal Relationships

• In a study of terminally ill patients with cancer, greater than 90% thought it was very or extremely important to:
  • Feel appreciated by family
  • Be able to say good-bye to people closest to them
  • Know that family left behind would be all right without them
Personal Relationships

- Relationships can change when family members become caregivers
- Friends may not know how to offer support
- Potential Questions to Ask
  - *Who are the most important people in your life and how are they dealing with your illness?*
  - *What worries do you have about your loved ones both now and after you are gone?*
  - *Are you able to talk to the important people in your life about your illness and the fact that you may die?*
The concepts of religion and spirituality are not the same, although some patients use the terms interchangeably.

- Individuals can be self-described as highly spiritual, but participate in no organized religion, and vice versa.
Spirituality

• Spirituality
  • Refers to the *personal understanding* of the relationship between one’s self to others and the universe.

• Religion
  • Refers to a *culturally grounded* system of beliefs concerning the cause, nature and purpose of the universe and individual human life.
Spirituality

When faced with a life-limiting illness, there are common questions/concerns of patients that transcend all religions, and cultures:

- What is my purpose?
- Does life have any meaning?
- Why do people suffer?
- Is suffering a punishment?
- What is the meaning of death?
- What happens after death?
Spirituality

Potential Questions to ask

- Do you see spirituality or religion as a source of support at this time?
- Do you have spiritual or religious beliefs that impact your decisions?
- Are there any faith rituals that can promote comfort?
- Do you have spiritual concerns that you would like to discuss with a chaplain?
Financial Concerns

- Financial concerns can add stress to an already stressful situation and may even change a patient’s decision for care.
- Family members may lose their job and become a caretaker, etc.
- Potential Questions to ask
  - Are you worried about finances now or in the future?
  - Are there ways in which your financial situation is acting as a barrier for you to get the help you need?
Coping Style

The ability of a patient to cope with impending death depends on:
- Past physical and emotional experiences
- Life-long psychological coping skills and personality
- Support from family, friends, community, health professionals

The range of responses extends from the extraordinary (where personal growth in the dying process is possible), to the adaptive, to the dysfunctional.
- Physicians can play a large role in helping patients cope in adaptive ways that promote growth near the end-of-life.

Block SD. JAMA 2001, 13:2898-2905
Coping Style

Two common means of dealing with a life threatening illness:

- **Coping**: active problem solving to deal with problems as they arise; generally a healthy and adaptive response.
- **Defending**: avoiding realities to maintain psychological balance. Defenses can be *adaptive* — reducing stress to allow for fuller psychological adjustment or *maladaptive* — preventing necessary adjustment to reality in the face of important life changes or decisions.
Coping Style

• Denial can be a positive or negative coping mechanism.
  
  • **Positive**—an adaptive response, allowing the patient time to adjust to a new reality.
  
  • **Negative**—a maladaptive response, impairing judgment in medical decision making or life planning.
Coping Style

When should denial be confronted?
- Only when it is a maladaptive response with negative health or social consequences:
  - Failing to complete legal/financial plans for family well being
  - Requesting CPR days before death from a fatal illness
Coping Style

• Potential Questions to ask
  • How have you coped with stressful events in the past?
  • What do you do when you feel overwhelmed?
  • Do you have people that you rely on when things start to feel out of control?
What is the Physicians Role?

- Recognize that psychological and spiritual concerns can be very important to a patient’s sense of well-being
- Relieve physical pain and other distressing symptoms
- Create an environment of trust
- Listen for patient comments that suggest emotional pain
- Communicate effectively/honestly/openly
- Involve and support non-physician members of the care team
- Accept the limits of your ability to address psychosocial concerns
- Take care of yourself (see Self-Care module)
The dying experience

- The dying experience is comprised of physical, psychological, social, and spiritual losses and stressors.
  - The entirety of loss and stress is referred to as:

  **Total Pain or Suffering**

- Also referred to as emotional pain or spiritual pain.
All patients nearing the end of life suffer a cascade of losses:

- **Physical**: loss of limbs/organs, control over bodily functions, cognition
  - Examples: Losing a breast, unable to walk without assistance, incontinence

- **Psychological**: loss of future, self-image, emotional self-control, privacy, freedom
  - Examples: Will not live to see grandchildren; avoidance of friends, being naked in front of aides/nurses for bathing, toileting, etc
Loss and Grief

- **Social**: loss of family role, work role
  - Examples: Can no longer support family as head of household, feeling like a burden rather than a contributing family member
- **Spiritual**: loss of trust in higher power, sense of purpose and meaning
  - Examples: Questioning previously held faith in God; loss of hope for a better future.
Patients often have many stages of grief since they have many stages of loss.

Grief is defined as:

- A normal, multi-dimensional, unique, dynamic process of pervasive loss. \(^1\)
- A person's internal experience, thoughts and feelings related to the experience of a loss. \(^2\)

\(^1\) Jacob J. J Adv Nursing 1996;24:280-86.
\(^2\) Ross D. U MD medical resident palliative care training modules.
Loss and Grief

- **Anticipatory Grief**
  - Normal emotional preparedness in anticipation of death—experienced by both patient and family

- **Uncomplicated Grief**
  - 80-90% of bereaved individuals
  - Normal progression through psychological tasks or stages

- **Complicated Grief**
  - 10-20% of bereaved individuals
  - Maladaptive adjustment to death of a loved one
The following ‘stages’ of grief are commonly experienced—although not in a direct sequential order:

- Disbelief/shock
- Separation distress or yearning
- Anger
- Depressed mood or despair
- Ultimate acceptance of loss

Normal signs/symptoms

- Changes in weight (up or down) and sleep pattern (more or less)
- Fluctuating mood: good days and bad
- Auditory hallucinations: hearing the deceased’s voice
Normal Grief “Work”

- Accepting the reality of the loss
  - Overcome the normal denial of the loss
- Experiencing the pain of the loss
  - One must feel the pain of loss, before true acceptance can occur
- Adjusting to an environment without the deceased
  - Learning to take on new tasks; fill roles previously held by the deceased
- Emotionally relocate the deceased—move on with life.
  - Redirection of emotional energy away from the deceased and back to self; adjusting the relationship from one of presence with the deceased, to a memory of the deceased.
- Patients or families that do not experience the above are at risk for complicated grief
Complicated Grief

• Common features of complicated grief:
  • Sense of disbelief lasting > 6 months
  • Anger and bitterness
  • Recurrent pangs of painful emotions with intense yearning for the deceased
  • Preoccupation with thoughts of the loved one including intrusive, distressing thoughts about the death.

Complicated Grief

- Can lead to consequences for the person who is grieving, such as increased risk for:
  - Cancer
  - Heart disease
  - Depression/Suicide
  - Substance use disorders
  - Social/family/occupational dysfunction
  - Hospitalization
Complicated Grief - Risk Factors

- Who the deceased was
  - Loss of spouse or child most difficult
- Nature of the attachment
  - Clinging, ambivalent, abusive relationships
- Mode of loss
  - Traumatic, sudden deaths more difficult than chronic diseases
  - With chronic diseases, survivors have time to anticipate and psychologically prepare for the loss (anticipatory grief)
- Past history
  - Multiple losses, past poor coping with losses
- Psychiatric history
  - Personality disorders, pre-existing anxiety or depression
- Concurrent stressors
  - Multiple events affecting all aspects of the bereaved (social, financial, health, spiritual)

Complicated Grief–Risk Reductions

• Pre-Loss Interventions
  • Honest, open communication to prepare loved ones for impending loss
  • Helping to relive family guilt/anxiety about end-of-life decisions through physician leadership and support (see Goal Setting module)
  • Timely referral for hospice and/or psychological counseling services to provide support during the dying process
Complicated Grief–Risk Reductions

- **Post-Loss Interventions**
  - Education and normalization of the grief process
  - Supportive counseling: listening, validating reactions
  - Frequent assessment during first six months after loss for those individuals at high risk of complicated grief
  - Referral for psychiatric consultation:
    - Grief symptoms are impacting daily functioning
    - Suicidal ideation
Loss and Grief

• There is no set time course to arriving at acceptance of a loss. For some it is a few weeks to months, for others it occurs more slowly.
• For most patients, grief over the death of a loved one is permanent, in that the sense of loss is always present as a memory.
  • It is normal for feelings of loss and yearning to be triggered years following a death by seemingly trivial events.
• A complete psychosocial assessment is helpful to evaluate how your patient is dealing with the loss and grief s/he is experiencing.
You have been caring for a 63 yo male diagnosed with ALS one year ago. He lost the ability to walk 6 months ago. Currently, he is in the hospital with an aspiration pneumonia. When you come in to assess the patient today, he asks you, “Why is God punishing me like this? What did I do to deserve this disease?”

How do you respond?
Please refer to next slide
Answering the unanswerable

- Your most important job when confronted with these questions is to:
  - **Listen with empathy**: Sit down, allow silence, reflect and restate patient concerns
  - **Validate**: ensure that patients know you care about their non-medical concerns
  - **Treat the treatable**: pain, depression, nausea
  - **Involve others**: to support both the patient and yourself
Learning Points

List 3 new things you learned from this presentation.

1.
2.
3.