How to Manage Death and Dying on a Consult Psychiatry Service

Learning Objectives:

1) Understand how to approach and feel comfortable with the dying patient.
2) Learn to assess where the patient is at psychologically in this stage of their life.
3) Develop skills to help patients process their feelings and thoughts at the end of life.
4) Recognize and treat psychiatric comorbidities at the end-of-life.

Step 1: Setting the Scene

- Ensure privacy.
- Be physically present, in appropriate setting.
- Sit at the patient and family's eye level to facilitate comfort, eye contact, and communication through body language (1).
- Establish social supports and discuss in advance who the patient wants present/not present for this conversation.
- Make clear the intentions of the time spent: to be open to the patient's humanity and individual experience of their illness (2). The purpose is not to solve the patient's problems or address medical concerns but help synthesize and validate the patient's narrative (3).
- Our goal is: "To cure sometimes, to relieve often, to comfort always." – Hippocrates (4).

Step 2: Beginning the Conversation

- First, ask the patient about who they are or what is important to know about them.
- Next, ask the patient what is their understanding of their medical condition and prognosis.
- Then check in with the patient as to how much they wish to know & what they are hoping to get from meeting with psychiatry.
- Depending on where the patient is at (see Step 3 below) and what they want to talk about, make a space for the patient to express their feelings and thoughts.
- Keep in mind:
    - Use clear, simple, and direct communication, use the words "death" and "dying" and avoid euphemisms (5).
    - Develop and sustain trust (6).
    - Preserve dignity of the patient and family (6).
    - Encourage the patient and family to tell their story (6).
    - Make clear that you are here to understand & listen to the patient and their experience of illness. When conversing ensure that you are stopping often to validate and summarize the patient's concerns to ensure you are accurately understanding. This is therapeutic as it enables the patient to feel seen and enables them to articulate to themselves what their experience has been & what they are concerned about.

Step 3: Assessing the Patient's Psychological State

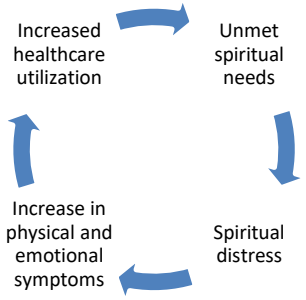
When assessing for causes of distress for patients facing end of life it can be useful to consider:

- Stages of Grief (7):
    - In Elizabeth Kubler-Ross's work *On Death and Dying*, she described common emotional themes based on interviews with terminally ill patients. These five stages, which are not universally experienced nor necessarily experienced sequentially, are: denial, anger, bargaining, depression, and acceptance.

  - Subsequent studies have reinforced that acceptance of illness and the fact that they are dying is a critical step.
- Erik Erikson's stages of development:
  - These are listed below and serve as a guide to understanding what key conflict a person may be facing depending on where they are in life (8). When facing death, however, whatever age and stage they may be, they are often suddenly faced with the final stage of integrity vs despair.

Developmental stage	Key conflict	Basic virtue
Infancy	Basic trust vs mistrust	Hope
Toddler	Autonomy vs shame and doubt	Will
Preschool-age	Initiative vs guilt	Purpose
School-age	Industry vs inferiority	Competency
Adolescence	Identity vs identity confusion	Fidelity
Young adulthood	Intimacy vs isolation	Love
Middle age	Generativity vs stagnation	Care
Older adulthood	Integrity vs despair	Wisdom

- The Patient's Existential/Spiritual State
  - Spirituality is defined by the US consensus committee as "the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred" (9). Spirituality may or may not be include religion, which is a social institution joined or organized by people with shared beliefs, traditions, and rituals.
  - Dimensions of spirituality to discuss with patients (10):
    - Importance of spirituality and religiousness to the patient.
    - Religious affiliation and degree of participation.
    - Religious/spiritual coping with the stress of illness (positive or negative).
    - Religious/spiritual values and beliefs related to their illness.
    - Religious/spiritual practices.
  - Spiritual distress can result from:
    - Fear of death or the unknown.
    - Negative feelings including anger, guilt, blame.
    - Loss of self, relationships, or meaning.



(11)

  - Recommended strategies for discussing spiritual issues at end of life (3)
    - Make a connection: attentive listening, acknowledging concerns, naming emotions, making empathic statements.
    - Avoid providing premature reassurance that can shut down further helpful discussion.
    - Follow hints to clarify the patient's beliefs, concerns, and needs.
    - Appreciate the limits of medical training in regard to facing death, and avoid the pitfall of trying to solve the patient's problems or resolve unanswerable questions (no theological debates).

- Mobilize sources of support for patients.

Step 4: Identify Psychiatric Disorders at the End of Life

- Psychiatric disorders are as or more prevalent at end of life as the general population. However, mental health treatment is underutilized (12).

Disorder	Screening instruments	Clinical Pearls
Anxiety	• Fear of Disease Progression Scale • Generalized Anxiety Disorder Scale (GAD-7) • State-Trait Anxiety Inventory (STAI)	• Determine if the anxiety is an exacerbation of a pre-existing anxiety disorder, an adjustment disorder, or if the anxiety is related to the disease or treatment itself. • Consider psychological factors: fear of death, fear of separation, fear of disease progression, fear of financial consequences (13).
Depression	• Hospital Anxiety and Depression Scale (HADS) • Two-item depression inventory (depressed mood and loss of interest in activities) (PHQ-2)	• Beware the false assumption that depression is an unavoidable part of dying, or the opposite, pathologizing a normal response to terminal illness. • Anhedonia, self-esteem, hopelessness, and prolonged social withdrawal are symptoms more closely associated with depression than grief and may be helpful to distinguish the two in palliative care (14).
Delirium *Subtypes: Hypoactive, hyperactive, Mixed*	• Confusion Assessment Method (CAM) • Montreal Cognitive Assessment test (MOCA) • Mini Mental Status Exam (MMSE)	• Delirium is the most common neuropsychiatric complication in advanced illness, with prevalence rates of 19 to 58% (13). • Delirium is inextricable to the dying process, however, may also be reversible (15). • Assessment: Conduct a clinical interview, obtain collateral, and systematically assess patient's cognition. • Prevention is key: see National Institute for Health and Clinical Excellence (NICE) guideline for the prevention of delirium (16).

Step 5: Providing Support and Treatment

- Reframing Hope:
  - Use wish statements to share a patient's hope without setting unrealistic expectations, i.e., "I wish that you could also be able to go home." This creates common ground to progress to co-creating a clinical path forward (3).
  - Keep in mind that disagreements with recommended medical interventions at end of life are more commonly about different values rather than lack of facts.
- Specific Treatments for Psychological Distress:
- Increase patient's sense of dignity:
  - "For palliative patients, a sense of dignity is the feeling that they are respected and perhaps even more so, worthy of respect, despite the physical betrayal of their bodies and the psychological distresses their illnesses bring" (6).
  - Questions from Dignity Therapy (17):

Can you tell me a little about your life history; particularly those parts that you either remember most or think are the most important? When did you feel most alive? Are there specific things that you would want your family to know about you, and are there things you would want them to remember?

What are the most important roles (e.g., family, vocational, community service) you have played in life?
Why are they so important to you and what do you think you accomplished in those roles?
What are your most important accomplishments and what do you feel most proud of?
Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?
What are your hopes and dreams for your loved ones?
What have you learned about life that you would want to pass along to others?
What advice or words of guidance would you wish to pass along to your _____ (son, daughter, husband, wife, parents, other[s])?
Are there words or perhaps even instructions you would like to offer your family, in order to provide them with comfort or solace?

- Meaning-based Therapy
  - Core concepts (18):
    - The will to meaning – finding meaning in life is a basic human drive.
    - Life has meaning – even in the final months/days/hours of life.
    - Freedom of will – we have a choice to make in how we find meaning in life and frame our suffering.
  - Join in search for meaning through (18):
    - Historical sources – life as a legacy.
    - Attitudinal sources – how do we choose to approach the different aspects of life and suffering.
    - Creative sources – explore creative endeavors as well as responsibilities in life.
    - Experiential sources – connecting with life through love, beauty, and humor.
- Treat Psychiatric Comorbidities
  - Anxiety
    - Pharmacological:
      - Not much good evidence in the literature, though one systematic literature review found that five studies showed morphine and midazolam were effective for dyspnea, anxiety, or terminal restlessness; furthermore, eight studies showed that midazolam was safe and did not shorten survival (19).
    - Nonpharmacological (6):
      - Shift from focusing on antecedents and maladaptive coping to helping patients 'contain' anxiety and manage the practical concerns and fears around dying.
      - Address the fear of death, help find a way to conclude unfinished business, and restructure expectations for life to include short-term goals.
  - Depression
    - Pharmacological (6):
      - Few studies in the terminally ill, therefore extrapolate from general population.
      - A role for psychostimulants (dextroamphetamine, methylphenidate) exists due to the limited time-frame in which we have in this population to achieve effectiveness of medication.

        - Nonpharmacological (6):
            - Multiple modalities of psychotherapy can be effective, most important factor is staying with the patient as they approach the end-of-life so that they don't feel abandoned.
            - Teaching distraction and relaxation techniques can be helpful.
    - Delirium
        - Pharmacological (6):
            - Haloperidol can be used (can be administered subcutaneously if needed) (20).
            - Second-generation antipsychotics (ie, risperidone and olanzapine) may have better side effect profiles and still be effective.
            - Benzodiazepines may be used in terminal delirium to reduce distress.
            - If terminal delirium and distress cannot be managed, sedation with agents like midazolam or propofol may be appropriate.
        - Nonpharmacological (6):
            - Involving family to be present and help reorient the patient.
            - Maintain hydration and nutrition.
            - Address anxiety through frank discussions and supportive therapy.
            - Address disorientation with visual aids (clocks, calendars, familiar items).

Step 6: Practice Self-Care

- Remember that what we do in our daily practice is hard.
- Give yourself grace – allow for time to reflect, debrief, get support, and generally take care of yourself.
- It's okay to grieve yourself.

References

1. Wenrich MD, Curtis JR, Shannon SE, Carline JD, Ambrozy DM, Ramsey PG. Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death. Arch Intern Med. 2001 Mar 26;161(6):868-74.
2. Daaleman TP, Usher BM, Williams SW, Rawlings J, Hanson LC. An exploratory study of spiritual care at the end of life. Ann Fam Med. Sep-Oct 2008;6(5):406-11.
3. Lo B, Ruston D, Kates LW, Arnold RM, Cohen CB, Faber-Langendoen K, Pantilat SZ, Puchalski CM, Quill TR, Rabow MW, Schreiber S, Sulmasy DP, Tulsky JA; Working Group on Religious and Spiritual Issues at the End of Life. Discussing religious and spiritual issues at the end of life: a practical guide for physicians. JAMA. 2002 Feb 13;287(6):749-54.
4. Amonoo HL, Harris JH, Murphy WS, Abrahm JL, Peteet JR. The Physician's Role in Responding to Existential Suffering: What Does It Mean to Comfort Always? *Journal of Palliative Care*. 2020;35(1):8-12.
5. Collins A, McLachlan S-A, Philip J. How should we talk about palliative care, death and dying? A qualitative study exploring perspectives from caregivers of people with advanced cancer. Palliative Medicine. 2018;32(4):861-869.

6. Chochinov HM, Breitbart W. Handbook of Psychiatry in Palliative Medicine. 2nd ed. New York, New York: Oxford University Press, Inc; 2009.
7. Copp G. A review of current theories of death and dying. J Adv Nurs. 1998 Aug;28(2):382-90. doi: 10.1046/j.1365-2648.1998.00794.x. PMID: 9725736.
8. Orenstein GA, Lewis L. Eriksons Stages of Psychosocial Development. [Updated 2022 Nov 7]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK556096/
9. Piana, R. Consensus Conference Definition of Spirituality. The ASCO Post. Dec 10, 2015. [accessed Feb 2, 2023]. Available from: https://ascopost.com/issues/december-10-2015/consensus-conference-definition-of-spirituality.
10. Steinhauser KE, Fitchett G, Handzo GF, Johnson KS, Koenig HG, Pargament KI, Puchalski CM, Sinclair S, Taylor EJ, Balboni TA. State of the Science of Spirituality and Palliative Care Research Part I: Definitions, Measurement, and Outcomes. Journal of Pain and Symptom management. 2017; 54(3):428-440.
11. Edwards A, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. Palliative medicine. 2010 Dec;24(8):753-70.
12. Kadan-Lottick NS, Vanderwerker LC, Block SD, Zhang B, Prigerson, HG. Psychiatric disorders and mental health service use in patients with advanced cancer. Cancer. 2005;104: 2872-2881.
13. Levenson, James L. The American Psychiatric Publishing Textbook of Psychosomatic Medicine and Consultation-Liaison Psychiatry. 3rd ed. Washington, DC: American Psychiatric Pub., 2019.
14. Periyakoil VS, Hallenbeck J. Identifying and managing preparatory grief and depression at the end of life. Am Fam Physician. 2002; 65:883–890.
15. Bush SH, Tierney S, Lawlor PG. Clinical Assessment and Management of Delirium in the Palliative Care Setting. Drugs. 2017; 77(15):1623-1643.
16. National Institute for Health and Care Excellence (NICE). Delirium: prevention, diagnosis and management in hospital and long-term care. London: NICE; 2023 Jan 18. PMID: 31971702.
17. Chochinov HM. Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life. Journal of Clinical Oncology. 2005; 23(24):5520-5525.
18. Breitbart WS, Poppito SR. Individual Meaning-Centered Psychotherapy for Patients with Advanced Cancer: A Treatment Manual. New York, New York: Oxford University Press, Inc: 2014.
19. Jansen K, Haugen DF, Pont L, Ruths S. Safety and Effectiveness of Palliative Drug Treatment in the Last Days of Life – A Systematic Literature Review. J Pain Symptom Management. 2018; 55(2):508-521.e3.
20. Bartz L, Klein C, Seifert A, Herget I, Ostgathe C, Stiel S. Subcutaneous Administration of Drugs in Palliative Care: Results of a Systematic Observational Study. J Pain Symptom Management. 2014; 48(4): 540-547.