Compassionate Care of the Terminally Ill

Jeff C. Huffman, M.D., and Theodore A. Stern, M.D.

How can you be most helpful to a person in need when hope appears lost? What is the best way to deliver news of a terminal diagnosis? Should you assess someone for depression when he or she is terminally ill? How can you develop a reasonable and thoughtful plan for end-of-life care?

Every clinician at one time or another faces these important questions. In the treatment of terminally ill patients, the health professional needs many skills: the ability to deliver bad news, the knowledge to provide appropriate optimal end-of-life care, and the compassion to allow a person to retain his or her dignity. The following vignette describes the case of a gentleman nearing the end of his life. The discussion and annotated references that follow should help the reader to best handle the complex issues that are involved in the care of the dying patient.

Case Presentation

Mr. A, a 47-year-old man without prior psychiatric problems, was admitted to the hospital for continued treatment of widely metastatic colon cancer. Since his diagnosis 2 years earlier, he had undergone a sigmoid resection, radiation therapy, chemotherapy, and a more extensive abdominal resection. His cancer continued to spread, however, and he was admitted for symptoms suggestive of a small-bowel obstruction.

During the hospitalization, he required antibiotic treatment of an abdominal abscess and subsequently received intraperitoneal chemotherapy. Despite these interventions, his tumor burden remained high, and the treatment team felt that there was little else to be done; he was thought to have less than 6 months to live. The team broached this issue with Mr. A, but was unsure about how much information to give him. Psychiatric consultation was requested to evaluate his depression and “pathological denial.”

On consultation, Mr. A was noted to be somewhat irritable, and he endorsed frustration at his loss of function secondary to his illness. He reported numerous sources of stress—he recently lost his job as an executive, he was embroiled in a stressful divorce with his ex-wife, and he was becoming impotent as a result of his treatments. When asked if he felt sad, he replied, “Well of course I’m sad! The impotence has got me down, and I know that 4 or 5 years from now, I might not even be around to see my kids.” Low energy, reduced concentration ability, psychomotor slowing, and decreased appetite were noted; these symptoms appeared to have progressed over the last 6 months as his illness worsened. He also lost interest in the great majority of his former hobbies. When asked about his medical illness, he reported that there would likely be another surgery in his future to try to “cure this thing once and for all.” However, he tended to ruminate on both the past and the present, and acknowledged that he had little to look forward to. He was lucid and fully ori-
present; a screening mental status examination found that his cognition was intact.

**How Should Information About a Diagnosis With a Terminal Prognosis Be Given to a Patient? How Much Information Should Be Given?**

While there is no single best way to decide what information to share, when it should be communicated, and how to best relay the information, several important principles can help in such a difficult situation.

Both studies of terminal illness and our own clinical experience have found that the majority of patients wish to know the full truth about their condition. Furthermore, in most cases, patients who are told their diagnosis in an up-front, clear manner have better emotional adjustments to their situation than those who are not told about their condition. By providing direct, clear information in a compassionate manner, and by making clear to the patient that everything possible will be done to provide medical and emotional support, physicians can elicit trust and reduce anxiety.

Of course, there may be special circumstances that affect the rate and the manner in which the information is relayed. If the physician has an opportunity to discuss the possible results of a given diagnostic test before the test is done or before the results are available, he or she can help prepare the patient for all possibilities (good and bad) and assess the probable response to bad news. If the patient displays a catastrophic reaction or frank denial at the possibility that the test will return grave results, the consultant may wish to consider the best way to tell the patient about such results.

Cassem, in the *Massachusetts General Hospital Handbook of General Hospital Psychiatry*, recommends relaying negative information to patients through a brief, rehearsed initial statement that succinctly communicates the news and clearly indicates that the treatment team is committed to the ongoing care and support of the patient: “A typical delivery might go as follows: ‘The tests have confirmed that your tumor is malignant [the bad news]. I have therefore asked the surgeon [radiotherapist, oncologist] to come by to speak with you, examine you, and make his recommendations for treatment [we will do something about it]. As things proceed, I will be by to discuss them with you and how we should proceed [I will stand by you].’ Silence and quiet observation at this point yield more valuable information about the patient than any other part of the exchange.”

In the case of Mr. A, the patient did not appear to understand the gravity of his condition. The first order of business would be to determine why Mr. A did not understand his situation—was this denial or simply a lack of information? It would be useful to determine what the treatment team had already told Mr. A about his diagnosis and prognosis. If Mr. A had received limited or conflicting information about his prognosis, the consultant could help the team open a discussion of Mr. A’s condition and its prognosis.

If, on the other hand, Mr. A had been repeatedly told his prognosis but seemed to be in denial, a different approach would be in order. In this case, the physician could avoid meeting the denial head-on, but might instead ask about the emotional impact of the illness and hospitalizations on Mr. A. This could then allow a discussion of Mr. A’s fears and fantasies about his condition and its consequences. It would be useful to consider a referral to a counselor, therapist, or another trusted individual to allow Mr. A to slowly let his guard down and to discuss the realities and emotions of his situation.

**How Can One Tell the Difference Between the Normal Grief Associated With Dying and the Condition Known as Depression? Which of These Did Mr. A Present With?**

Grief and depression share a number of features. Both are associated with periods of significant sadness, crying spells, periods of social withdrawal, and decreases in sleep, concentration, or energy. However, there are a number of important differences between a process of normal grief and a syndrome of major depression that require treatment.

Grief is characterized by episodic waves of sadness that can be initiated by thoughts of impending death or by a person/event that will be missed. However, this sadness is not pervasive, and it is balanced by the patient’s ability to experience pleasure and to look forward to future events. A global loss of interest in pleasurable activities does not occur, and feelings of hopelessness are transient. There may be passive wishes for death to come quickly, but these too are fleeting, and there are no active plans for a hastened death.

In contrast, depression is characterized by unremitting sadness and by an inability to enjoy activities that would usually be experienced as pleasurable. Feelings of hopelessness are prolonged, and suicidal ideation is more active and more persistent. The patient with major depression is frequently unable to look to the future.

Chochinov and colleagues found that the single question, “Are you depressed?” was quite effective in diagnosing major depression among terminally ill hospice patients. However, the psychiatric consultant can increase diagnostic accuracy by assessing each of the above-mentioned domains to determine whether a patient’s distress is the result of grief or depression.

In the case of Mr. A, his symptoms were more consistent with depression than with normal grief. His denial of his illness made it difficult to fully assess his ability to look forward to the future, but he acknowledged that he
had little to look forward to. Furthermore, he had persistent anhedonia, and the vignette seemed to indicate that his symptoms were more persistent than episodic. Given his persistent anhedonia, neurovegetative symptoms, and hopelessness, he met criteria for major depression and should have received treatment for his depression.

What Characteristics of Treaters Are Important in the Care of Dying Patients?

Cassem and Stewart detailed essential features of the delivery of care to dying patients. These include:

1. **Competence.** Skillful treaters allay anxiety and allow the best possible medical outcome. Just because a person has terminal illness does not mean that clinicians should not use their highest level of medical skill to maximize comfort and reduce distress. Competent treaters use their skills to optimize pain control, to treat comorbid reversible medical conditions, and to consider psychiatric diagnoses. Dying patients are greatly comforted when they feel that their physician is knowledgeable and has developed a comprehensive plan of care.

2. **Concern.** Much is taught about the need to protect oneself against becoming “too wrapped up” in the care of one’s patients. However, true empathy and connection are necessary to provide good care for such patients, and rather than be avoided, such traits should be standard doctor’s tools used to cure, to soothe, and to improve the lives of patients. Often, family members and patients may avoid talking about painful feelings of impending loss. Treaters, by discussing their own feelings about the patient’s loss and by asking how others are dealing with the impending loss during meetings with patients and families, can show their own concern and allow patients and families to grow closer.

3. **Comfort.** A primary issue. Physical discomfort can contribute to psychological distress and inhibit a healthy grief process. Assessment and treatment of pain should be complete and thorough. Treatment of pain with narcotics, nonsteroidal anti-inflammatory drugs (NSAIDs), adjunctive agents, acupuncture, biofeedback, and other remedies is crucial in the care of the dying. Treatment of low energy, shortness of breath, and psychiatric symptoms is also key. Where patients go to spend their final days is another vital issue that can either enhance the final days of life or make them uncomfortable.

4. **Communication.** Communication with the dying should focus far more on the art of listening than on the art of speaking. When the treaters does speak, it should be to help patients tell the story of their life (their accomplishments, their interests, their regrets, their hopes, the people in their life, and the details of their spiritual life). By spending time with a patient, by listening intently, and by helping the patient make meaning of life and death, a treater can facilitate therapeutic communication.

Treaters can also help by sharing Elisabeth Kubler-Ross’ 5-stage model of the response to impending death. The stages of this model outline a course of emotions often experienced by patients and family members as they go through the process of grieving. These 5 stages (denial, anger, bargaining, depression, and acceptance) outline the course of normal/healthy bereavement.

While individuals rarely pass through these stages in a linear way, knowledge of the stages can be helpful to treaters when identifying a patient or family member who seems “stuck” in a particular stage. Furthermore, knowledge of this model can normalize the denial, anger, or sadness of such a patient and help treaters see that their patient may be going through a normal and healthy process. For patients, knowledge of these stages can let them know that the process of grief is not uncharted territory and that peace and acceptance can be found at the end of their emotional suffering.

Interestingly, a recent article by Curtis and colleagues asked patients with 3 end-stage illnesses [COPD, AIDS, and cancer] about important physician skills in end-of-life care. The authors found many similarities across diseases, but also found some disease-specific differences in the skills perceived to be most crucial in end-of-life care. The patients with COPD in this study reported that a physician’s ability to provide education about their disease and prognosis was very important (often those with COPD had not been well informed of the generally irreversible nature of their illness). Patients with AIDS targeted pain control as a major issue, while patients with cancer valued physicians who were able to help them maintain hope in the face of their illness. Therefore, while the properties of compassion, communication, and continuity were crucial for all patients, there appeared to be specific domains of care that may be more important based on the nature of one’s illness.

How Can a Clinician Be Helpful to a Patient Who Is Terminally Ill?

The following are 4 ways in which a clinician can be helpful to a patient who is terminally ill:

1. **Aid the psychological and spiritual coping process.** The consultant can engage in discussions that allow the patient to reveal the important psychological, social, and spiritual aspects in his or her life. In an article that discussed end-of-life care, Block described that a systematic assessment of these domains allows treaters to gain a sense of the patient’s coping strengths and vulnerabilities. The consultant might ask about some of the following:

   **Life story.** What are you proudest of? What legacy would you like to leave? What would you like your family to remember about you? Do you have any regrets? Is there anything you would like to accomplish with the remainder of your life?
Relationships. Whom do you cherish most? Have you been able to tell them? Is there anyone you would like to reconcile with? Are there any friends you hope to see? How can you help your family prepare for your death?

Coping. What are your biggest strengths? What difficult things have you gotten through in your life, and how did you get through them? When have you been most discouraged over the course of this illness? How do you think you will cope with the time ahead? What is scary about the time ahead of you?

Spirituality. Are you a religious person? Do you believe in God? What is your relationship with God? Do you feel able to communicate with him? What do you imagine will happen to you when you die? Do you feel that God is happy with you, angry with you, or feels some other way? Why?

These questions can be very therapeutic in themselves, and they allow a person to reflect on the accomplishments and relationships that have been important to him or her. They also allow some attention to the things that the person would still like to achieve emotionally and interpersonally in the time remaining. Furthermore, as noted by Block, they can help treaters to better understand a person’s coping strategies, allowing for optimal care.

2. Assess and treat psychiatric illness. Psychiatric illness is common among patients with terminal illness. Such illnesses should be identified as the treatable syndromes that they are, rather than as “expected” outcomes of terminal diagnoses. Major depression is experienced by approximately one fourth of patients with cancer, with rates increasing as the disease worsens. Other terminal illness is similarly associated with elevated rates of major depression. Furthermore, one quarter of terminally ill patients also experience significant anxiety symptoms. Untreated pain, dyspnea, and nausea can exacerbate abnormal mood and anxiety.

Delirium is also common in patients with terminal illness and it often goes unrecognized (or is misdiagnosed as psychosis or anxiety). A mental status examination and careful monitoring of the patient’s level of consciousness, orientation, and agitation throughout the day can help identify delirium in this at-risk population. When delirium is diagnosed, the cause of the delirium should be determined. It is crucial to distinguish between irreversible causes of delirium (e.g., brain metastases and organ failure) and those causes that can be treated. Treatable causes of delirium in this population include, but are not limited to, contributions from medications (benzodiazepines, anticholinergics, steroids, and narcotics), electrolyte disturbances (especially those of calcium and sodium), metabolic disturbances (especially from thyroid dysfunction and glucose abnormalities), and infections. It should be noted that most causes of delirium are multifactorial, and, therefore, even if some contribution to the delirium is derived from an irreversible medical condition, the treatment team should search for reversible conditions that can contribute to clouding of the mental status.

Treatment of these conditions is, in general, similar to the treatment received by those who are not terminally ill, although special considerations should be made for predicted life span, organ failure, and use of concomitant medications. Depression can be rapidly treated with stimulants, specifically methylphenidate or dextroamphetamine, beginning at 2.5 to 5 mg/day. If the predicted life span is greater than 4 to 6 weeks, a standard antidepressant, such as an SSRI, can be used. If the patient is taking several medications, citalopram or sertraline may be the favored SSRIs because of their minimal interaction with the cytochrome P450 system.

Free-floating anxiety should also be assessed carefully. Anxiety can result from pain, delirium, inadequate information, or a variety of other sources. Anxiety in nondelirious patients can be treated with benzodiazepines. If the anxiety is situation-specific, or of relatively short duration, short-acting benzodiazepines (such as lorazepam) can be administered on an as-needed basis. If the anxiety is more persistent, longer-acting agents, such as clonazepam, can be given as a standing dose. As with depression, if the patient’s condition is associated with a life span of greater than 4 to 6 weeks, SSRIs can be useful, especially in the treatment of well-defined anxiety syndromes, such as panic disorder.

Delirium should be symptomatically treated with antipsychotics. By the intravenous route, haloperidol is an excellent choice because it results in virtually no extrapyramidal symptoms (EPS); QTc intervals should be followed while this medication is being administered to facilitate prevention of torsades de pointes. Benzodiazepines should be avoided in delirious patients, as they tend to increase confusion and may further disinhibit the patient or worsen agitation. For delirious patients who are able to take medications by mouth, atypical antipsychotics are also appropriate and have relatively few adverse effects. It should be noted, though, that these are symptomatic treatments and that the diagnosis and treatment of reversible causes of delirium are crucial.

3. Maximize comfort. In addition to diagnosing psychiatric illnesses, the consultant should also remain aware of other factors that contribute to impairments in a patient’s comfort. Pain control is of utmost importance in the care of the dying patient, and many studies have found that pain is undertreated in this population. The psychiatric consultant can be helpful to the treatment team by identifying ongoing pain. The consultant can remind the treatment team that much higher doses of
narcotics may be needed in chronically ill patients with acute pain; consultants can also relieve anxiety about “causing addiction” in the terminally ill. Furthermore, adjuncts to narcotic medications (e.g., NSAID, tricyclic antidepressants, anticonvulsants, physical therapy, biofeedback, and massage) can be considered for any patient with ongoing pain.

“Comfort” extends far beyond analgesia. Symptomatic discomfort from nausea, hiccups, or dyspnea can be assessed and treated. Adequate food, drink, and hygienic care can lead to significantly improved mood, self-esteem, and dignity. Furthermore, a patient’s physical location can have a tremendous impact—does this person wish to die at home or in comfort at hospice rather than in a hospital? Each of these factors needs to be considered in the treatment of the terminal patient.

4. Treat the treaters and family members. Physicians who treat patients with terminal illness undergo significant stress. They may feel helplessness at their inability to cure the patient or anger at themselves for not catching the illness at an earlier stage (or anger at the family or the patient for not coming for treatment sooner). Conversely, treaters can feel tremendous grief with the loss of a patient with whom they have had a long relationship or a strong alliance. Psychiatric consultants can help treaters to identify their grief and can encourage them to share these feelings of loss with the patient, with other colleagues, and with supervisors.

Psychiatric consultants can also help family members cope with the impending loss of a loved one. In considering the emotional state of a person with terminal illness, it is often helpful to consider the effects of the family members on the patient and vice versa. By observing the interactions of a patient with family, the consultant can become aware of long-standing grudges or new difficulties in communication that can make the process of coming to closure at the end of a life more difficult.

Family members or friends who serve as regular caregivers to a terminally ill patient have substantial stress and elevated rates of depression. The psychiatric consultant can be helpful by inquiring about stress and depressive symptoms in caregivers, and can be useful by suggesting “breaks,” additional help, or a different system of care if appropriate and if the caregiver is open to such suggestions. The consultant can also help to reduce feelings of guilt in caregivers if they do decrease their involvement in direct caregiving.

The case above provides an opportunity for the consultant to be helpful in a number of ways. By exploring Mr. A’s understanding of his condition and his feelings about the future, by assessing him for psychiatric illness and other etiologies of discomfort, and by supporting the treatment team and his family members, the consultant can have a significant impact on his care.

Mr. A was started on sertraline therapy for his depressive symptoms. Fortunately, despite his level of denial, he was willing to accept a referral for psychotherapy. The treatment team’s hope was that such therapy would allow Mr. A to reduce his level of denial about his medical condition and therefore process his impending death more fully. Such changes would allow Mr. A to have a more fruitful end-of-life process.

Drug names: citalopram (Celexa), clonazepam (Klonopin and others), dextromethorphan (Dexedrine and others), haloperidol (Haldol and others), lorazepam (Ativan and others), methylphenidate (Ritalin, Concerta, and others), sertraline (Zoloft).

REFERENCES


ANNOTATED BIBLIOGRAPHY

Breaking Bad News
—A review of the published literature that discusses the optimal delivery of bad news. The authors selected the 13 most common recommendations from these articles and examined the evidence that supports such recommendations. In general, the authors found that, despite many articles written on the topic, little empirical research has been done to examine the effectiveness of commonly recommended strategies for breaking bad news.
—A brief, useful guide that provides a strategy for breaking bad news well, using the mnemonic ABCDE (Advance preparation, Build a therapeutic environment/relationship, Communicate well, Deal with patient and family reactions, Encourage and validate emotions). In addition, the authors discuss a number of strategies that clinicians may use to further help their patients who suffer.
—An informative study of 120 cancer patients who received bad news about their illness from physicians. The patients were asked to describe the interaction with the physician when they received bad news and to indicate whether they were satisfied with the interaction. Patients were most satisfied when the physician held the conversation in a comfortable environment, spent sufficient time to allow for adequate discussion, and made efforts to empathize with the patient.
Caring for Terminally Ill Patients

—The best-known volume on this topic. It introduces Kubler-Ross’ 5-stage response to impending death: denial, anger, bargaining, depression, and acceptance. The book also gives sample interviews with terminally ill patients and discusses therapy with patients facing death.

—A comprehensive discussion of the many aspects of caring for patients who are terminally ill. Psychosocial, spiritual, medical, and ethical aspects are all considered.

—An accessible and practical article that outlines a number of strategies for discussing end-of-life care issues with patients. A case-based discussion highlights the authors’ points about introducing and explaining palliative care to patients and their families. The authors also discuss strategies for responding to difficult patient questions about end-of-life topics.

Block SD. Psychological considerations, growth, and transcendence at the end of life. JAMA 2001;285:2898–2905
—A well-written, interesting, and thorough discussion of important medical and emotional issues at the end of life with a pertinent review of the literature. It is written from the perspective of a patient, his son, and the treating physician, and it uses a case vignette and interviews with all 3 to frame the important end-of-life issues. Many of the suggestions in this rounds report are adapted from this paper.

—A clear and comprehensive overview of the optimal treatment of terminally ill patients. The authors discuss the treatment of symptoms (e.g., pain, nausea, and depression) that can cause distress and lower quality of life. They next discuss the importance of communication with patients and families and describe the utility of making hospice referrals when appropriate. The article ends by detailing how physicians can avoid burnout by attending to their own feelings of helplessness, grief, and loss.

—This article details the most-valued domains of physician skill in end-of-life care. Among patients with 3 different terminal illnesses, many similarities were found in the domains considered most valuable, but there were also significant diagnosis-specific differences.

Grief and Depression

—A useful article that describes the 3 phases of normal grief and indicators of pathological grief reactions. The authors describe practical methods of distinguishing between normal bereavement and abnormal syndromes that require treatment. In addition, the article emphasizes the significant negative impact of abnormal reactions to grief on emotional and physical health.

—An interesting brief report that found that a single question about depressed mood was both reliable and accurate in determining the presence of depression among terminally ill patients. This question (essentially, “Are you depressed?”) correctly identified the presence or absence of depression in all 197 patients in the study.

Krigger KW, McNeely JD, Lippmann SB. Dying, death, and grief: helping patients and their families through the process. Postgrad Med 1997;101:263–270
—A useful article that describes how primary care physicians can help patients and families through the grief process. The authors recommend educating patients about the normal stages of bereavement, providing support and grief counseling as appropriate, and evaluating patients for abnormal grief that may require pharmacotherapy, referral, or hospitalization.

—A clear, well-written review on the diagnosis and treatment of depression in the terminally ill. The authors review barriers to diagnosis, characteristics of depression that distinguish it from normal grief, and assessment of suicidal ideation in this population. Treatment with medication and psychotherapy are also reviewed. Helpful charts allow easy access to the material, and 3 case vignettes are used to frame the pertinent issues.