

# EPEEC-O

Education in Palliative and End-of-life Care - Oncology

## **Participant's Handbook**

Module 14

## **Physician- Assisted Suicide**

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## Abstract

Most physicians have received one or more requests to help a patient end his or her life prematurely. This module focuses on the skills that the physician can use to respond both compassionately and with confidence to a request, not on the merits of arguments for or against legalizing physician-assisted suicide (PAS) or euthanasia. To respond effectively, physicians must know the reasons why patients ask for assistance. Depression, psychosocial factors, and anticipated distress are common reasons, but current physical suffering can also be a factor. Physicians need to be able to assess the root causes of the specific request, make a commitment to the patient's care, address each of the patient's sources of suffering, educate the patient about legal alternatives, and seek counsel from colleagues. The vast majority of requests for PAS or euthanasia should abate when approached in this way.

## Key words

Abandonment, burden, consultation, control, deliberation, depression, dignity, euthanasia, fears, listening, pain, physician-assisted suicide, psychological, social, spiritual, suffering

## Objectives

The objectives of this module are to:

- Define physician-assisted suicide (PAS) and euthanasia.
- Describe their current legal status.
- Identify root causes of suffering that prompt requests.
- Understand a 6-step protocol for responding to requests.

## Clinical case on trigger tape

J.W. is a 33-year-old attorney for a struggling Chicago-based entertainment company. Prostate cancer was detected 9 years ago. HIV status and Non-Hodgkin's lymphoma were diagnosed three months ago. He is doing better than you expected but is suffering from depression. He has declined counseling and has tried but rejected two different antidepressants. He fears losing control of his mind and ability to care for himself. He wants a way to avoid the fate he fears, and he asks the doctor about physician-assisted suicide.

## Introduction

Suffering has always been a part of human existence. Requests to end suffering by means of death through both physician-assisted suicide and euthanasia have likely occurred since the beginning of medicine. Patient requests for assistance in suicide are relatively common.<sup>1,2</sup> A national survey of physicians who care for terminally ill patients found that over 18% had been asked by a patient at least once to assist in suicide and over 11% had been asked to give a lethal injection. Cancer specialists are especially likely to encounter these issues. In a 1996 survey, more than half of responding oncologists reported having received a request for assisted suicide or euthanasia.<sup>3</sup>

Physical pain, dependency, and depression are all associated with consideration of euthanasia or physician-assisted suicide.<sup>4,5</sup> While concerns about pain are common among people who are seriously ill, published studies have found pain not to be a dominant factor motivating people to seek or commit assisted suicide. Clinical depression and hopelessness have both been associated with the desire for a hastened death among cancer patients.<sup>6,7,8</sup> Issues of dependence on others and loss of autonomy have contributed to the suicides of terminally ill cancer patients who were receiving palliative care. A desire to control the circumstances of death was an important factor in the patients' decisions in a survey of Oregon nurses and social workers who cared for hospice patients who died by legally prescribed medication.<sup>9</sup> Similarly, loss of control, being dependent on others, and being a burden were the most frequently perceived causes of patients requesting assistance with suicide in a survey of Washington physicians.

Physical symptoms such as pain, dyspnea, and fatigue are common in patients with cancer and become more prevalent in advanced stages of disease.<sup>10,11,12,13,14</sup> The same is true for the syndrome of depression.<sup>15</sup> These sources of suffering do more than erode the quality of people's lives. Pain, fatigue, depression and self-rated assessments of health have all been shown to correlate with shorter survival.<sup>16,17,18,19</sup>

Despite its prevalence among patients with serious illness, clinical depression is often unrecognized. Because many of the constitutional symptoms of depression, such as loss of appetite, fatigue, disturbance of sleep, diminished libido, are all attributable to cancer or its treatment, the diagnosis may be obscured. Oncologists more readily diagnose depression when patients exhibit outward manifestations, such as crying and sad affect.<sup>20</sup> The response to a single question, "Are you depressed?" has been shown to correlate well with longer survey tools in diagnosing depression.<sup>21,22</sup> Inquiring about whether a patient feels a sense of hopelessness is also an effective screening tool for depression.<sup>23</sup>

Patients with advanced, incurable illness may experience 'total pain' that has physical, emotional, social, and spiritual dimensions.<sup>24</sup> The nature of suffering entails a sense of impending disintegration of the person and a felt loss of meaning and purpose in life.<sup>25,26</sup> Social suffering can derive from a sense of being a burden to one's family or society.

While unrelieved physical suffering may have been greater in the past, modern medicine now has more knowledge and skills to relieve suffering than ever before. Today, specialists in palliative care believe that if all patients had access to careful assessment and optimal symptom control and supportive care, the suffering of most patients with life-threatening illnesses could be reduced sufficiently to eliminate their desire for hastened death. Even when the desire persists, avenues other than physician-assisted suicide or euthanasia are available to remedy suffering and avoid prolonging life against the patient's wish.

This module presents an approach for responding compassionately and competently to such requests. *The focus is not on the debate to legalize PAS or euthanasia, but rather on the practical steps that a physician can take to assess the patient's request, begin to address its root causes, and ensure optimum quality of end-of-life.*

## **Why patients ask for physician-assisted suicide**

Requests by a patient for assistance in suicide can be startling and understandably are often emotionally difficult for physicians. It is in nature of empathy that a physician feels suffering when a patient is suffering enough to seek early death. And at times to a physician's ears, a patient's expression of a wish to die can sound like a condemnation of the care they are receiving. However hard for the physician to hear, it is essential for such requests to be understood as invitations for communication and seen as therapeutic opportunities. The courage it takes for an ill and vulnerable person to make such a request of his or her physician is, in itself, evidence of the patient's trust and opens the door to deeper conversation.

Advocates of legalizing physician-assisted suicide assert that patients may feel abandoned if their doctor declines to write a lethal prescription. A countervailing concern is that agreeing to a request could curtail rather than open communication and that in even considering assisting a patient in suicide, a physician risks reinforcing the sense of helplessness, hopelessness and loss of worth that may underlie the patient's despair. Given the risk that either approach may worsen the suffering, start instead by listening and exploring the patient's motivations.<sup>27</sup>

Patients ask physicians about physician-assisted suicide (PAS) for a variety of reasons. It is a rare patient with a life-threatening illness who doesn't think about suicide, if only in passing. Some patients may approach the physician about PAS with the intent of 'thinking out loud' about their current and future condition. Others may raise the question based on lifelong values. For some, a request for PAS is sign that unmet needs have built up to an intolerable level. For all patients, the request for PAS should prompt the physician to assess the reasons for it. Patients make requests for many different reasons that may arise from physical, psychological, social, or spiritual suffering, or practical concerns. Each person will have a unique set of needs and reasons why he or she would like to hasten death. In many surveys of patients' reasons, unrelieved psychosocial and

mental suffering is the most common stimulus for requests. Studies have documented that patients who are depressed are more likely to have made serious inquiries about PAS or euthanasia. Fear of future suffering, loss of control, indignity, or being a burden are also prominent reasons for requests.<sup>9,33</sup>

Physical suffering, including pain, is a less frequent motivator than many think. In one above noted study, pain alone was a motivator in 3% of requests, pain was one of several motivators in 46% of requests, and in the remaining 51% of requests pain was not cited as a factor at all. Nonetheless, the contribution of physical suffering is important because it is often treatable (see EPEC-O Module 2: Cancer Pain Management and EPEC-O Module 3: Symptoms).

The fear of being a burden and loss of independence are the most important correlates of a desire for hastened death, more distressing for many patients than physical symptoms. It remains crucial to address physical symptoms in cases of requests for hastened death. But, in relative terms, the other is more important. The key point for physicians is that phrases such as "we can control your symptoms, even if we have to sedate you" or "we can keep you comfortable" may not be reassuring to the majority of patients. Rather, exploring the psychosocial dimension and addressing those concerns will be most fruitful.

## The legal and ethical debate

The debate about the legalization of active steps to intentionally end life as a means to end suffering remains controversial. Because of the added risk of misunderstanding or overriding the patient's wishes, there is currently less support for euthanasia than for physician-assisted suicide. Nonetheless, both requests do occur and physicians need to know how to respond to either type of request.

In any discussion of physician-assisted suicide or euthanasia, it is important that the terminology be clear. Euthanasia is defined as *the act of bringing about the death of a hopelessly ill and suffering person in a relatively quick and painless way for reasons of mercy*. Physician assisted suicide is defined as *the act of physicians providing the means for a patient to hasten his or her death*. Although they may have similar goals, physician-assisted suicide and euthanasia differ in whether or not the physician participates in the action that finally ends life.

In **physician-assisted suicide**, the physician provides the necessary means or information and the patient performs the act.

In **euthanasia**, the physician performs the intervention.

In the current debate, there are two principles on which virtually all agree. First, physicians have an obligation to relieve pain and suffering and to promote the dignity of dying patients in their care. Second, the principle of patient bodily integrity requires that physicians respect patients' competent decisions to forgo life-sustaining treatment.

An important event in the present debate occurred in 1997, when the United States Supreme Court recognized that there is no federal constitutional right to physician-assisted suicide but did affirm that state legislatures may choose to legalize it. As of early 1999, Oregon is the only state that has voted to legalize PAS. In contrast to the PAS debate, the right to palliative care is uniformly acknowledged. The same US Supreme Court Justices' concurring opinions supported the right of all Americans to receive quality palliative care.

## **Professional competence**

As most physicians are likely to receive a request for hastened death, every physician must be capable of dealing with these difficult requests in a way that responds to the needs and expectations of the patient and offers the best possible care that is both ethical and legal.

The ability to respond to requests for hastened death with realistic alternatives requires a working knowledge of all aspects of palliative care. The physician must follow usual standards for communication, know how to provide aggressive symptom control and supportive care, and be skilled at approaches to withdraw or withhold life-sustaining interventions (see EPEC-O Module 7: Communicating Effectively; EPEC-O Module 8: Clarifying Diagnosis and Prognosis; EPEC-O Module 2: Cancer Pain Management; EPEC-O Module 3: Symptoms; and EPEC-O Module 11: Withdrawing Nutrition, Hydration). A physician will want to be aware of the legal issues described in the original *EPEC Curriculum's* Plenary 2: Legal Issues in End-of-life Care.

As effective approaches for responding to suffering may be time consuming, physicians will be more effective if they work collaboratively with other health care disciplines in an interdisciplinary team. As some requests for PAS or euthanasia can be intense, even for physicians who are skilled and experienced, access to consultative palliative care expertise, both physicians and programs, as part of the spectrum of contemporary health care is essential (see EPEC-O Plenary 2: Models of Integrated Care).

## **6-step protocol for responding to requests for physician-assisted suicide or euthanasia**

Any request for PAS should always be taken seriously. Response should be immediate and compassionate. Six steps can be identified for responding to such requests:

1. Clarify the request.
2. Assess the underlying causes of the request.
3. Affirm your commitment to care for the patient.
4. Address the root causes of the request.
5. Educate the patient and discuss legal alternatives.

## 6. Consult with colleagues.

While each step will be discussed in this module in sequence, as with other clinical protocols, these steps should integrate smoothly and flexibly into actual practice as issues arise. Depending on the particular case, some steps may be implicit or accomplished in a few words, while others may be complex and require considerable time to respond.

### **Step 1: Clarify the request**

When a patient first raises the issue it is necessary to clarify just what the patient means. Some people assume that if there is a routine treatment available for a condition that threatens their life, they have little choice other than to accept it, as if doing less than everything to prolong life is tantamount to suicide. By making it clear that it is legally and ethically permissible to decline treatments – even antibiotics for infection and tube nutrition and hydration – and allow a natural death to occur, people may be satisfied that their life will not be prolonged against their wishes.<sup>28</sup>

Sometimes people will use provocative statements, such as, “I hope you’ll help me die when it’s time” or “Please promise not to let me suffer,” as if to test the physician’s willingness to talk about their fears of dying badly. It is important to understand whether they are actually referring to physician-assisted suicide or euthanasia or adequate analgesia. Many people do not make these distinctions and while expressing themselves in the language of assisted-suicide; their request is to be assured of a way to escape suffering if it becomes unbearable. Such people are commonly reassured to learn that good palliative care extends to whatever treatments are necessary to alleviate physical distress. At the same time, people may need assurance that effective pain management, including “a morphine drip” or sedation when necessary, is not a euphemism for euthanasia, but rather good medical care for a serious medical problem.

In discussing sedation with patients, the practice must be distinguished from euthanasia. Sedation for otherwise intractable symptoms is consistent with the treatment of pain in burn units and surgical suites. The same principle of careful titration of anesthetic agents as necessary for adequate treatment and patient comfort applies to palliative sedation.<sup>29</sup>

When cases of requests to hasten death are presented in ethical papers or in public debates, they often look like ethical puzzles that involve complex, irresolvable psychosocial issues and existential suffering. In the real world of patients’ lives and clinical practice, these cases are not esoteric ethical or clinical puzzles, but the pleas of fearful, vulnerable people who are looking to their physicians for reassurance, affirmation and practical help.

When a patient asks for hastened death, listen carefully to the nature of the request. Ask open-ended questions in a calm and nonjudgmental manner to elicit specific information about the request that is being made and the underlying causes for it. While some physicians fear that talking about suicide or hastened death will increase the likelihood



that the patient will act, this fear has not been substantiated. An open discussion is more likely to reduce the intensity of the request.

Once the underlying reasons are known, more directed questions can be asked. Several examples, and the common areas to which answers may point, follow:

MD: “What makes you ask that?”

- Desire for a pain-free death
- Control over the dying process

MD: “What do you expect will happen without PAS?”

- Understanding and expectations of the illness
- Expectation of what dying will be like

MD: “What type of assistance do you want?”

- Pills, injection

MD: “Who do you want to be involved? Why?”

- Self, family member, physician

MD: “When do you think you want to die?”

- Now
- At some later point

MD: “What do you hope to accomplish?”

- Freedom from pain, disability, bankruptcy, dependency, indignity
- Removing burden on others

The answer to the question, “When do you think you want to die?” will provide some indication of acuity. “What do you hope to accomplish?” will provide some understanding of the patient’s reasoning and what he or she is hoping for. During the course of the questioning, it is particularly important to learn whether the patient is imagining future symptoms or other conditions that are either unlikely or easily preventable.

As you listen to the answers, use the therapeutic effect of empathic listening. Avoid endorsing the request for PAS in a way that confirms the patient’s perception that his or her life is worthless. Similarly, avoid rejecting the request when it is first heard as this will often serve to close rather than open discussion. Remember that empathizing is not the same thing as agreeing. Premature affirmation of any perspective can propel both parties to stark choices.

Only when the patient's point of view has been characterized will it be possible to talk about what suffering means to the patient and what assurances can or cannot be given.

## **Personal biases vs. therapeutic listening**

To respond effectively to the needs of the patient, the physician must be aware of his or her own biases and the potential for counter-transference. If the idea of suicide is offensive to the physician, the patient may feel his or her disapproval and worry about abandonment. Conversely, if the physician feels it would be best for everyone if the patient were to die soon then the patient may sense this and become more concerned about being an unwelcome burden.

Be open to the possibility that your personal reactions to the patient's suffering may give insight into his or her experience. For example, if the physician feels weighed down by meeting with the patient, perhaps the patient is depressed.

In making the request, the patient is opening a door for communication. The therapeutic response to requests for assisted suicide or euthanasia begins with listening. Possibly because listening involves little outward motion, to the casual observer it seems passive, and its value as an active therapeutic intervention is often unrecognized.

In actuality, the physician's ability to listen and commitment to stay involved are the main components of an effective response. The therapeutic power of listening must not be underestimated.<sup>30</sup> Confronted with a request to hasten death, many times the critical early intervention consists of a handful of minutes spent listening to a patient's fears, acknowledging the person's suffering, coupled with the physician's firm commitment to remain involved, continuing to try new ways to improve the person's quality of life, and supporting the patient and family during this difficult time.

The physician-patient relationship is the most powerful therapeutic resource to bring to suffering. By carefully assessing and effectively treating pain and other symptoms a person's confidence in their physician's knowledge and skills is reaffirmed. Similarly, exploring a patient's suffering and fears engenders confidence in the physician's compassion and willingness to be there in the hard times that may lie ahead.

Often a person's suffering is rooted in fears of the future; the person can tolerate the current situation but worries what will happen if things get worse. Physicians can use this aspect of suffering to therapeutic benefit. It is often possible to diminish an acutely anxious patient's distress and improve the patient's sense of control by drawing attention to the present moment in which their discomfort is tolerable, if only barely, and by emphasizing that life is a series of present moments. The future-based nature of most suffering allows physicians to inform and affirm for patients that there is *always* something they can do to decrease the severity of pain or other symptoms and support patients and families through these difficult times. Outlining some specific steps that can be taken if pain or other cancer-related symptoms worsen can be reassuring for patients

and their loved ones. Patients who fear dying in uncontrolled physical agony are often reassured that palliative sedation is available for situations in which suffering cannot be otherwise controlled.<sup>31</sup>

Social suffering that comes from the felt loss of meaning – a sense of having nothing to contribute and being merely a burden to others – is not without therapeutic response. A loved one's illness and care almost inevitably does impose burdens on people's family. All who love the person are affected by their illness in emotional and practical ways. Serious illness disrupts plans and sometimes derails long-held aspirations. Here again, there are no pat answers. While it is essential for physicians to affirm their commitment to suffering patients, they need not shoulder these responsibilities alone. The multidimensional suffering of progressive cancer is best addressed by interdisciplinary approaches to care.<sup>32</sup> Hospice and palliative care programs can respond in skillful ways, often identifying ways of lessening the burden and enabling families to care well and with love without losing their own lives in the process.

## **Step 2: Assess the underlying causes of the request**

A request for PAS may indicate a failure to address the full scope of a patient's needs. Focus on all 4 dimensions of physical, psychological, social, and spiritual suffering as well as practical concerns (see EPEC-O Module 1: Comprehensive Assessment).

### **Assess for clinical depression**

Among all the psychological and physical possibilities, give particular consideration to the possibility of clinical depression or anxiety, as research indicates correlation between requests and their presence.<sup>9,33</sup> When evaluating psychological and social issues; explore the patient's fears about his or her future. Clinical depression occurs frequently and is both under-diagnosed and under-treated. It can be a source of intense mental suffering and a barrier to completing life closure and achieving a 'good death.'

Diagnosis of depression is more challenging in patients with advanced illness, since the physical symptoms typically associated with depression (eg, changes in appetite, weight, energy level, libido, or sleeping) frequently occur in these patients as a result of their illness.

Studies have shown that the screening question, "Do you feel depressed most of the time?" is highly sensitive and specific in the medically ill. Feelings of pervasive helplessness, hopelessness, and worthlessness are not normal. Do not assume they are situational and leave them unattended (see EPEC-O Module 3: Symptoms).

### **Psychosocial suffering, practical concerns**

Emotional and coping responses to life-threatening illness may include a strong sense of shame, feelings of not being wanted, and difficulties coping. Adjustment to the loss of

previous function, independence, control, and/or self-image may be difficult. Each change may lead to tensions within relationships that further increase isolation and misery.

Worries about practical matters (e.g., who the caregivers will be, how domestic chores will be done, who will care for dependents and pets, etc.) can create considerable distress. If support is not forthcoming or is insufficient, suffering may ensue or increase. Approaches to the assessment of psychosocial issues and practical concerns are covered in EPEC-O Module 1: Comprehensive Assessment.

## **Physical suffering**

A host of physical symptoms may accompany advanced illness. These may include pain, breathlessness, anorexia/cachexia, weakness/fatigue, nausea/vomiting, constipation, dehydration, edema, incontinence, loss of function, sleep deprivation, etc. Their presence, particularly if they are unmanaged for long periods, may markedly increase suffering. Approaches to the assessment of physical issues are covered in EPEC-O Module 1: Comprehensive Assessment. The management of pain is discussed in EPEC-O Module 2: Cancer Pain Management. The management of other common physical symptoms is discussed in EPEC-O Module 3: Symptoms.

## **Spiritual suffering**

The prospect of dying may evoke seemingly unresolvable existential concerns that are then experienced as suffering. As illness advances and disability increases, the patient's sense of his or her meaning, value, and purpose in life may all come into question. If there is a sense of abandonment or punishment by God, faith and religious beliefs may be eroded and anger may ensue. Approaches to the assessment of spiritual issues are covered in EPEC-O Module 1: Comprehensive Assessment.

## **Fears for the future**

In addition to current concerns, many patients are fearful about what the future will be like. They may worry about pain and other symptoms, loss of control or independence, abandonment, loneliness, indignity, loss of self-image, and being a burden to others. While their thoughts may be unrealistic in the setting of quality care, many have witnessed suboptimal care in others that fuels their fears and fantasies.

Direct questions may be adequate to assess a patient's fears. If not, discussing a series of scenarios and preferences, as is done during advance care planning, may be helpful. When personal values and goals of care are being discussed, clarify the things the person most wants to avoid. This may help to preempt unrealistic fears (see EPEC-O Module 13: Advance Care Planning).

### **Step 3: Affirm your commitment to care for the patient**

Patients facing the end of life often have fears of abandonment. Listen to and acknowledge expressed feelings and fears. Make a commitment to help find solutions to the issues of concern, both current and anticipated. Reinforce that you want to continue to be the patient's physician until the last possible moment. Explore options to allay immediate concerns and fears.

As a request for hastened death affects everyone who is close to the patient, a commitment to the patient also affirms a commitment to the family and those close to the patient, including other caregivers.

### **Step 4: Address the root causes of the request**

This section provides a general framework for addressing some of the potential root causes for a request for hastened death in each dimension of suffering. Start by discussing the patient's health care goals and preferences, explaining palliative care approaches and services, and describing the legal alternatives to PAS. Remember that some patients may not trust either individual health caregivers or the health care system to meet their needs. If possible, it helps to discuss this lack of trust with the patient and at the outset, so that the issues can be understood, if not dealt with, early (see EPEC-O Module 13: Advance Care Planning; EPEC-O Module 1: Comprehensive Assessment; EPEC-O Module 9: Negotiating Goals of Care; and EPEC-O Module 12: Conflict Resolution).

### **Address psychological suffering**

As psychological suffering leads to many of the requests for physician-assisted suicide or euthanasia, its management warrants considerable attention. Start by assessing and managing any depression, anxiety, or delirium aggressively (see EPEC-O Module 3: Symptoms).

As each patient's emotional response to illness can be profound and coping responses varied, they will require careful exploration in a positive and understanding way. Supportive counseling, which involves active listening and acknowledgment of the patient's feelings, may be woven into general care, or it may be provided more intensively through dedicated individual or group counseling. Social workers and chaplains trained in supportive counseling can provide considerable assistance. Referral to trained counselors, psychologists, or psychiatrists may be required if the issues are complex and/or the risks high.

People can be helped to see their physical dependence as an unavoidable consequence of their illness, rather than as a personal failing. Clinicians can foster a sense of dignity by the manner in which care is provided. In coming to know the patient as a person, the physician acknowledges the uniqueness and inherent worth.

Death awaits us all. Therefore, if hope were to reside solely in avoiding death, ultimately all hope would be lost. In practice, it is often possible for people who are approaching the end of life to reframe hope, discovering meaningful opportunities that still exist.<sup>34</sup>

Physicians can assist patients to identify achievable goals, such as participating in meaningful events, engaging in life review, completing personal affairs and relationships, and feeling prepared to leave this life.<sup>35</sup>

## **Address social suffering, practical concerns**

Stresses and conflicts in the social or practical aspects of a person's life can have profound effects on his or her will to live. Express interest and inquire in detail about this aspect of the patient's life:

- What is the patient's family situation? Does he or she live with someone? Are family members supportive? Are there unresolved issues?
- How is the patient's financial situation? Is health insurance available and sufficient?
- Are legal affairs in order? Does the patient have a living will, power of attorney for health care, power of attorney for business affairs, last will and testament?
- Where would the patient like to receive care? Who is there to help? Who will the caregivers be? Is there tension over the caregiving role for either party?
- Who attends to domestic chores such as cooking, cleaning, shopping, banking, and/or bill payments?
- Are there any dependents the patient cares for, or pets? Who will care for them if the patient is not able to?

Consider requesting assistance from other members of the health care team (e.g., social work, nursing, chaplains, occupational therapy, etc). Additional resources for help and support may be available in the community, through a health care institution, or from a local hospice or palliative care program.

## **Address physical suffering**

Multiple studies indicate that patients with life-threatening illnesses have many unaddressed physical issues. If left unmanaged for long periods, each can add considerably to a patient's sense of suffering.

Today, medicine has more knowledge and tools to manage physical symptoms than ever before. Pain management is discussed in detail in EPEC-O Module 3: Symptoms. Each symptom needs to be pursued aggressively and successful management often requires extensive and careful thought and individual clinical trials until symptoms are brought under control..

Function is critical to maintaining independence. Psychiatrists, nurses, and physical and occupational therapists may be helpful and knowledgeable about the exercises and aids that can be used to optimize and maintain function and to ensure safety.

Sexuality and intimacy are integral aspects of each one of us, particularly through touch and the closeness to partners and family members we cherish. Illness and disfigurement may change the way people are able to interact. To establish individual desires and tensions, facilitate discussions between partners and key family members. Help them to look for alternatives that may be comforting.

## **Address spiritual suffering**

The spiritual dimension of human experience is universally challenged in the face of a life-threatening illness. Each person has a sense of meaning and purpose to his or her life, and a sense of where he or she fits into the grand scheme of things. This may have a frankly religious orientation or may be expressed through faith or a personal sense of spirituality. Nevertheless, the transcendental dimension is present in each one of us, and it is critical that this dimension be explored when a patient requests PAS or euthanasia.

Helping patients to establish or reestablish a sense of meaning and purpose is often fundamental to the relief of spiritual suffering. Encouraging them to reminisce with family and friends; assisting with life closure, gift giving, and creation of legacies may also be helpful.

Some physicians feel comfortable dealing with spiritual suffering. Others feel inexperienced and out of their depth. As these issues are critical and may be very time consuming, a skilled hospice chaplain who works with a psychiatrist or psychologist skilled in end-of-life care may bring considerable support to both the patient and the physician.

While it would be ideal if the needed skills came from the patient's own pastor, do not assume that all members of the clergy are equally comfortable with the care of patients with advanced life-threatening illness. Like physicians, many have not received adequate training in chaplaincy issues and are ill equipped to deal with the profound conflicts surrounding requests for physician-assisted suicide or euthanasia.

## **Address fears**

### **Fear of loss of control**

The autonomy and control that each one of us has over our lives and affairs is central to our personhood. While this need for control varies in some cultures, it is a central feature of Western society. For many, independence is profoundly challenged by illness that is debilitating and deprives them of mastery or control over their day-to-day activities and their sense of future.

This fear of loss of control may be further heightened by fears that their expectations and needs won't be addressed, or fears that people will do things to them that they don't want (e.g., forced feeding, invasive procedures, life-sustaining therapies, etc.).

The specific issues that are most important for each person to control are unique to that individual. They may include things, such as the ability to choose day-to-day activities and experiences that are meaningful, choices for therapies, settings of care, caregivers, etc.

The physician can be instrumental in helping the patient to continue to realize as much control as possible, given the changes in function that are likely to occur. This may take unusual flexibility on the part of the physician and the health care team. Educate and help the patient plan for aspects of medical care that are under his or her control (e.g., the ability to accept or refuse any medical intervention, life-sustaining therapies, etc.).

Encourage the patient to select personal advocates and proxy decision makers, prepare advance directives, and plan for death. This planning can include funeral plans, wills, and disposing of personal belongings after death. Teach family members and caregivers alternate approaches to caregiving that optimize patient participation in decision making, i.e., instead of 'doing without asking,' encourage family and caregivers to 'ask before doing.'

## **Fear of pain and other symptoms**

While patients may find current symptoms acceptable, they frequently fear a future where symptoms will be out of control and unbearable, particularly when they are dying. Reassure the patient that almost all symptoms can be well controlled. As appropriate, discuss alternate approaches to symptom management, including anesthesia. Ensure that patients and families know that pain ordinarily does not get suddenly worse as death approaches. Help them to understand the difference between pain and terminal delirium, particularly if they have known someone else who had a difficult death. As many patients fear adverse effects of medications, particularly drowsiness and confusion, discuss their management should they occur.

The possibility of end-of-life sedation, should pain or other symptoms be unbearable for the patient and unmanageable by experts, may be explored with the patient and family during advance care planning discussions. Some patients and families will find the possibility reassuring; others will not want to consider it.

Most importantly, during all of these discussions, make a commitment to keep working to manage the symptoms until they are satisfactorily controlled. This is a critical piece for patients who may fear being told, "I'm sorry, there's nothing more we can do."

## **Fear of being a burden**

In several studies, one of the things patients fear most about a life-threatening illness is the prospect of being a burden to others. This is, in some ways, a corollary of the fear of



losing control, particularly as our culture generally does not value being dependent on others.

Try to establish why the patient does not want to be a burden. If there are caregiving issues, facilitate a discussion between the patient and family. In many cases, families are willing and eager to care for the patient, and their desires simply remain unspoken. If patients and families are worried that family members will not have enough skill to provide adequate care, suggest home hospice care. One of the fundamental goals of the home hospice team is to help educate, train, and supplement the family in the care of the patient. Alternate care settings can be arranged as a backup if care at home does not go as planned. Home hospice agencies must make provisions for brief periods of respite care if it is needed. If there are financial issues, help the patient find information and resources that will be acceptable—many people are unaware of the services available. Social workers and nurses, who can help find solutions to issues and provide training and backup to unskilled family members, can be a significant resource to the physician to help lessen the patient's fear of being a burden.

### **Fear of indignity**

Patients may fear the loss of their dignity. As this is a complex concept that may include elements of being dependent, loss of control, being a burden, being embarrassed, etc., explore what it means to the particular patient.

Once the issues are clear, explore approaches to caring and resources that can help to maintain dignity. Ensure that the patient, where possible, participates in decision making. Ensure that family members and caregivers know how to approach and address these issues. Ensure that everyone has permission for their roles and each task that they will do. Reassure the patient that he or she has dignity in your eyes.

### **Fear of abandonment**

For some patients, their worst possible fear is abandonment—by families, their friends, their physicians, or other health care professionals. This fear can be heightened by the realization that others are having difficulties coping with the illness and the changes it brings, or the role of being a caregiver.

Explore this fear in detail with the patient and family in a family conference. Try to establish how realistic the patient's concerns may be. If tensions seem high or there are indications that family and friends are not coping, a meeting with everyone may be helpful to assess the situation. If caregiving is becoming onerous, offer a respite or an alternate setting for care. As appropriate, try to connect families to available supports in the community, particularly those provided by the interdisciplinary teams available through hospice and palliative care programs.

Above all, when addressing fear of abandonment, the physician must be able to honestly reassure the patient about his or her plans for being involved in ongoing care. This will

involve being clear about what one can do as a physician and how the interdisciplinary team will be part of care.

## **Step 5: Educate the patient and discuss legal alternatives**

### **Deal with misconceptions**

When making a request for PAS, patients may have misconceptions about the benefits of their requested course of action. Some may be unaware of the emotional effort goes into planning for physician-assisted suicide or euthanasia; others may be unaware of the risk of emotional consequences to family and friends.

### **Legal alternatives**

Patients may also not be aware of the legal alternatives available to them. This may be particularly true if they have not participated in discussions to clearly define their goals of care and treatment priorities. As part of the process of discussion, planning, and decision making, the physician may wish to discuss the 4 following legal alternatives to PAS:

#### **Refusal of interventions**

Patients should be clear that they have the right to consent to, decline, or withdraw any intervention (e.g., surgery, chemotherapy, pacemakers, ventilators, medications including antibiotics, IV fluids) or settings of care (e.g., hospitalization) if any of them seem too burdensome. (See EPEC-O Module 11: Withdrawing Nutrition, Hydration). They should also be aware that their choices to decline particular therapies will not affect their ability to receive high-quality end-of-life care.

#### **Declining of oral intake**

Patients with advanced disease often lose appetite and/or thirst. Just like any other medical decision, a competent individual can determine what goes into his or her mouth. Based on the principle of bodily integrity, force-feeding is not acceptable.

To assist with decision-making, patients will usually benefit from knowledge that they will not suffer from dehydration or starvation. A detailed discussion of their potentially protective properties and the appropriate management of symptoms should they occur will usually allay fears and reduce anxiety considerably (see EPEC-O Module 6: Last Hours of Living).

As fluids and food are synonymous with life and central to many rituals and socialization, and culturally ingrained, family and caregivers will likely need considerable education and support if the patient decides to cease oral intake. Encourage them to always have food and water accessible so that the patient can change his or her mind at any time. Discuss the potential for anger and resentment if they persist in badgering or attempting

to force things on the patient. Above all, recognize their desire and need to give care and refocus them on activities that will be beneficial to everyone.

## **Palliation sedation**

For the rare patient with unbearable and unmanageable pain, or other intractable symptoms, who is approaching the last hours or days of his or her life, the induction and maintenance of a state of sedation may be the only remaining option. Sedation in the imminently dying is intended to produce a level of obtundation sufficient to relieve suffering without hastening death. This approach has an ethical basis that derives from the importance of intended effect over possible secondary and unintended consequences. (See EPEC-O Module 11: Withdrawing Nutrition, Hydration for a discussion of intended effects and unintended consequences.)

Before end-of-life sedation is considered, it should be clear to the attending physician, members of the health care team, and consultants with expertise in palliative care that all available therapies have been tried to their limits without benefit. Individual physicians should not consider this issue without consulting others. This is not an alternative to high-quality palliative care or limitations in available resources imposed by institutions or health care funders.

If no other options are apparent, consider how the patient and family might react to this option. Advance care planning discussions and recent statements they have made may provide guidance. If the team feels that the patient and family will not perceive the discussion as a sign of abandonment, discuss the option with them and solicit their opinion. Before making a decision, it should be clear to everyone that the intent in offering sedation is to make the patient comfortable during the last days of his or her life when all other alternatives have not been successful. If anyone perceives that the intent of sedation is to kill the patient and not simply relieve suffering, the approach should not be pursued.

If the patient and family find the option acceptable and the patient chooses to receive sedation, intermittent or continuous intravenous or subcutaneous infusions of midazolam, lorazepam, propofol, or barbiturates have been used successfully to induce sedation and reduce awareness.

Opioids are not recommended if the primary goal is to induce sedation. However, if the patient has been in pain, opioids will need to be continued so that the sedated patient will not experience pain. Follow standard opioid dosing guidelines and alter doses if renal clearance decreases (see EPEC-O Module 2: Cancer Pain Management; EPEC-O Module 11: Withdrawing Nutrition, Hydration; and EPEC-O Module 6: Last Hours of Living).

If the patient dies while receiving sedation and appropriate doses of medication were used, the death is attributable to the underlying illnesses, not the sedation.

## Step 6: Consult with colleagues

A request for physician-assisted suicide may be one of the most challenging situations a physician will face in his or her practice of medicine. In such circumstances, the support and advice from colleagues and peers is critical. Unfortunately, it is in precisely these situations that physicians may hesitate to involve someone else. There may be several reasons for such reluctance. For some, the subject raises personal issues. Others may have the conviction that it is not appropriate to talk about death. A few may be reluctant to discuss requests for physician-assisted suicide or euthanasia because of the legal implications of the situation.

As requests for hastened death can have considerable personal, ethical, and legal ramifications, they should not be dealt with in isolation, but rather with the support and input of at least one trusted colleague or advisor. This person may be a mentor, a peer, a religious advisor, or an ethics consultant. Physicians may also find considerable support from nurses, social workers, chaplains, and other members of the interdisciplinary team who are involved in the patient's care.

### Response to persistent requests

Requests for physician-assisted suicide occur infrequently in most physicians' careers. Clinical experience suggests that most requests will resolve if unmet needs are addressed by using the approach offered in this module.

It also remains a fact that, as of early 1999, in all but Oregon, physician-assisted suicide remains illegal. When PAS requests are declined, full comfort care should continue and the professionals should continue to work in partnership with the patient and family.

However, despite doubled and redoubled efforts to assess and address root causes of suffering and provide high-quality palliative care, requests for physician-assisted suicide and euthanasia may occasionally persist. It is not the purpose of this introductory module to discuss such rare cases. These are likely to be complex and should be handled in consultation with experts.

### Summary

A request for physician-assisted suicide or euthanasia indicates unrelieved suffering. This module has presented a practical approach for physicians to use to respond to such requests. The physician needs to treat all requests seriously and compassionately, look for the root causes of the request, and work with the patient and others to relieve those root causes. Palliative care has never been as well developed and powerful in the history of medicine as it is now. Insisting on its widespread availability without legislative barriers and making use of its resources, will relieve most of the suffering that compels requests for PAS or euthanasia. Existing legal options for control and comfort can provide alternatives for most if not all patients who persist in their request for PAS or euthanasia.

## Key take home points

1. Physicians have an obligation to relieve pain and suffering, promote the dignity of dying patients, and assure continuity of care, avoiding abandonment of patients in their care.
2. Physicians must respect competent patients' decisions to forgo life-sustaining treatment.
3. In current day oncology practice, requests for assistance with suicide or for euthanasia occur. Such a request is not an indictment of the physician's practice, but rather part of the range of normal reactions that patients have to suffering caused by their symptoms and loss of function and to fears about their future.
4. Physicians can respond to these requests with honesty and compassion. In declining to write a lethal prescription, physicians can affirm the value of the person. Indeed, one of the risks of agreeing to assist the patient in suicide is reinforcing the sense of helplessness and hopelessness that the person may feel.

### Why patients request PAS

5. A request for physician-assisted suicide may be the first expression of unrelieved suffering.
6. Each person will have a unique set of needs and reasons for a request.

### Step 1: Clarify the request

7. Listen carefully to the nature of the request.
8. Explore the person's current suffering and fears. Try to understand the type of request that is being made and the underlying causes for it.
9. Be aware of personal biases and the potential for counter-transference.

### Step 2: Determine the underlying causes for the request

10. Clinical depression occurs frequently and is under-diagnosed, under-treated, and a frequent motivator for requests. Many constitutional symptoms of depression (e.g., fatigue, generalized weakness, anorexia, sleep disturbance, diminished libido) may be caused by illness or consequence of treatment. Assessing for hopelessness has been shown to be a valuable method of screening for depression in this population.
11. Emotional and coping responses to life-threatening illness may include a strong sense of shame, feelings of not being wanted, and/or inability to cope.
12. Worries about practical matters can create considerable distress.
13. Many patients are fearful about what the future will be like (pain and other symptoms, loss of control/independence, abandonment, loneliness, indignity, loss of self-image, being a burden).

### **Step 3: Affirm your commitment to care for the patient**

14. Acknowledge the patient's suffering and fears. Make a commitment to help find solutions to the issues of concern, both current and anticipated.

### **Step 4: Address the root causes of the request within the plan of care and through supportive counseling**

15. Knowledge of appropriate approaches for the withdrawal or withholding of life-sustaining interventions and aggressive comfort care is essential.
16. Assess and manage any anxiety, delirium, depression, physical symptoms, social dysfunction, and practical concerns.
17. Assess and address fears of being a burden, abandonment, loss of control, indignity, future pain, and other symptoms. Emphasize that it is entirely normal and not undignified to need help from others, especially when we are ill or old.
18. Assess the person's sense of loss of meaning and purpose. Explore ways of enhancing meaning by assisting with life review, and ways of contributing to others, such as recording of stories and life history and gift giving.
19. Offer anticipatory guidance (directly or through referral to palliative care programs) with personal and interpersonal issues of life completion and closure

### **Step 5: Educate the patient, discuss legal alternatives**

20. Patients should be clear that they have the right to consent to, decline, or stop any treatment or settings of care at any time if they seem too burdensome. Distinguish assisted suicide and euthanasia from avoidance of unwanted treatment, including otherwise routine treatments such as tube nutrition or antibiotics.
21. Patients may choose to decline regular oral intake of food and/or fluids.
22. For the rare patient with unbearable and unmanageable pain, or other intractable symptoms, who is approaching the last hours or days of his or her life, the induction and maintenance of a state of sedation is an ethical option when all other available and reasonable therapies have been tried unsuccessfully.

## Step 6: Consult with colleagues

23. Don't address requests for physician-assisted suicide in isolation – consult with trusted colleagues early. Hospice and palliative care clinicians are familiar with the fears and suffering that cause patients to request assistance with suicide.

## Pearls

1. Empathic listening can have a therapeutic effect.
2. Talking about suicide or hastened death, if the patient is thinking about it, may reduce, not increase their risk.
3. The question, “Do you feel depressed?” is a sensitive and specific screening question in the medically ill.
4. A sense of hopelessness can be a valuable marker for clinical depression in patients with advanced illness and symptoms of fatigue, generalized weakness, anorexia, sleep disturbance.
5. Pain and other physical symptoms are less frequent motivators than many think.
6. Fears and the need to have some control are fundamental issues.

## Pitfalls

1. Prematurely affirming any perspective can propel both parties to stark choices.
2. Delaying inclusion of other skilled members of the health care team.
3. Forgetting families and caregivers. They may need to be educated and supported, and their need to give care refocused.

## Resources

Back AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington State: patient requests and physician responses. *JAMA*. 1996;275:919-925.

Breitbart W, Jaramillo J, Chochinov HM. Palliative and terminal care. In: Holland J, ed. *Textbook of Psycho-oncology*. New York, NY: Oxford University Press; 1998: 437-449.

Chochinov HM, Wilson K, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry*. 1995;152:1185-1191.

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Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet*. 1996;347:1805-1810.

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Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med*. 1998;338:1193-1201.

Snyder L, Sulmasy DP; Ethics and Human Rights Committee, American College of Physicians-American Society of Internal Medicine. Physician-Assisted Suicide. *Ann Intern Med*. 2001;135:209-216.

Steinbrook R., Physician-Assisted Suicide in Oregon — An Uncertain Future, *N Engl J Med*. 2002;346:460-464.

Quill TE, Meier DE, Block SD, Billings JA. The debate over physician-assisted suicide: empirical data and convergent views. *Annals of Internal Medicine*. 1998;128(7):552-558.

Block SD, Billings JA. Patient requests to hasten death. Evaluation and management in terminal care. *Archives of Internal Medicine*. 1994;154(18):2039-2047.

Kohlwes RJ, Koepsell TD, Rhodes LA, Pearlman RA. Physicians' responses to patients' requests for physician-assisted suicide. *Archives of Internal Medicine*. 2001;161(5):657-663.

Burt RA. The Supreme Court Speaks — not assisted suicide but a constitutional right to palliative care. *N Engl J Med*. 1997; 337(17):1234-1236.

Quill TE, Lo B, Brock DW. Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA*. 1997;278(23):2099-2104.

Ganzini L, Harvath TA, Jackson A, Goy ER, Miller LL, Delorit MA. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. *N Engl J Med*. 2002;347:582-588.

Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon death with dignity act. *N Engl J Med*. 2000;342:557-563.

Chochinov HM. Dignity-conserving care--A new model for palliative care: helping the patient feel valued. *JAMA*. 2002;287(17):2253-2260.

Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. *Social Science & Medicine*. 2002;54(3):433-443.



## References

- <sup>1</sup> Back AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington State. Patient requests and physician responses. *JAMA*. 1996;275(12):919-925. [PMID: 8598619](#). [Full Text](#)

A mailed, anonymous questionnaire was sent to 1,453 households and 828 physicians to estimate how often physicians receive requests for physician-assisted suicide and euthanasia and to describe a case series of patient requests for physician-assisted suicide and euthanasia, including physician responses to these requests. In one year, 12% of responding physicians received one or more explicit requests for physician-assisted suicide, and 4% received one or more requests for euthanasia. The most common patient concerns at the time these requests are made are nonphysical.

- <sup>2</sup> Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med*. 1998;338(17):1193-1201. [PMID: 9554861](#). [Full Text](#)

To obtain national data on physician-assisted suicide and euthanasia in the United States, questionnaires were mailed to a stratified probability sample of 3102 physicians in the 10 specialties in which doctors are most likely to receive requests from patients for assistance with suicide or euthanasia. The response rate was 61 percent. A substantial proportion of physicians in the United States report that they receive requests for physician-assisted suicide and euthanasia, and about 7 percent of those who responded to our survey have complied with such requests at least once.

- <sup>3</sup> Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet*. 1996;347(9018):1805-1810. [PMID: 8667927](#).

Interviews, by telephone with vignette-style questions of 155 oncology patients, 355 oncologists, and 193 members of the public were undertaken to assess their attitudes and experiences in relation to euthanasia and physician-assisted suicide. Oncology patients experiencing pain are unlikely to desire these interventions while patients with depression are more likely to request assistance in committing suicide.

- <sup>4</sup> Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*. 2000;284(19):2460-2468. [PMID: 11074775](#). [Full Text](#)

A survey to determine the attitudes of terminally ill patients toward euthanasia and PAS, whether they seriously were considering euthanasia and PAS was administered to terminally ill patients and their primary caregivers. Of the 988 terminally ill patients, a total of 60.2% supported euthanasia or PAS in a hypothetical situation, but only 10.6% reported seriously considering euthanasia or PAS for themselves. In this survey, a small proportion of terminally ill patients seriously considered euthanasia or PAS for themselves. Over a few months, half the patients changed their minds. Patients with depressive symptoms were more likely to change their minds about desiring euthanasia or PAS.

- <sup>5</sup> Meier DE, Emmons CA, Litke A, Wallenstein S, Morrison RS. Characteristics of patients requesting and receiving physician-assisted death. *Arch Intern Med*. 2003;163(13):1537-1542. [PMID: 12860575](#). [Full Text](#)

To determine characteristics of patients who request physician-assisted suicide, specialties involved in care of the seriously ill were asked to describe the demographic and illness characteristics of the most

recent patient whose request for assisted dying they refused as well as the most recent request honored. Persons requesting and receiving assistance in dying are seriously ill with little time to live and a high burden of physical suffering.

- <sup>6</sup> Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284(22):2907-2911. [PMID: 11147988](#). [Full Text](#)

To assess the prevalence of desire for hastened death among terminally ill cancer patients and to identify factors corresponding to desire for hastened death, a prospective survey was conducted in a 200-bed palliative care hospital. In multivariate analyses, depression and hopelessness provided independent and unique contributions to the prediction of desire for hastened death, while social support and physical functioning added significant but smaller contributions.

- <sup>7</sup> Chochinov HM, Wilson KG, Enns M, Lander S. Depression, Hopelessness, and suicidal ideation in the terminally ill. *Psychosomatics*. 1998;39(4):366-370. [PMID: 9691706](#). [Full Text](#)

This study investigated the mediational hypothesis of hopelessness in predicting suicidal ideation in a group of 196 patients with advanced terminal cancer. Hopelessness was correlated more highly with suicidal ideation than was the level of depression.

- <sup>8</sup> Filiberti A, Ripamonti C, Totis A, et al. Characteristics of terminal cancer patients who committed suicide during a home palliative care program. *J Pain Symptom Manage*. 2001;22(1):544-553. [Full Text](#)

The possible vulnerability factors of suicide in five terminal cancer patients who committed suicide while they were cared for at home by well-trained palliative care teams were evaluated. Multiple vulnerability factors were present simultaneously in all patients. The loss of, and the fear of losing, autonomy and their independence and of being a burden on others were the most relevant.

- <sup>9</sup> Ganzini L, Harvath TA, Jackson A, Goy ER, Miller LL, Delorit MA. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. *N Engl J Med*. 2002;347(8):582-588. [PMID: 12192019](#). [Full Text](#)

The experiences of hospice practitioners with patients who requested physician-assisted-suicide were evaluated by mailed questionnaires. Since assisted suicide was legalized in Oregon, many hospice nurses and social workers have provided care for a patient who requested assistance with suicide. They rated desire for control as a very important reason for these requests.

- <sup>10</sup> Coyle N, Adelhardt J, Foley KM, Portenoy RK. Character of terminal illness in the advanced cancer patient: pain and other symptoms during the last four weeks of life. *J Pain Symptom Manage*. 1990;5(2):83-93. [PMID: 2348092](#).

The experience with advanced cancer patients referred to the Supportive Care Program of the Pain Service at Memorial Sloan-Kettering Cancer Center is reviewed. Prevalence of pain and other symptoms, patterns of opioid use and routes of drug administration, and the prevalence of suicidal ideation and requests for euthanasia are discussed.

- <sup>11</sup> Santiago-Palma J, Payne R. Palliative care and rehabilitation. *Cancer*. 2001;92(4 Suppl):1049-1052. [PMID: 11519032](#). [Full Text](#)

This article discusses the relationship between rehabilitation and palliative care and the possible role of rehabilitation interventions in the care of terminally ill patients.

- <sup>12</sup> Bruera E, Schmitz B, Pither J, Neumann CM, Hanson J. The frequency and correlates of dyspnea in patients with advanced cancer. *J Pain Symptom Manage*. 2000;19(5):357-362. [PMID: 10869876](#). [Full Text](#)

This prospective study assesses the frequency of moderate to severe dyspnea and the correlates of dyspnea in a population of ambulatory terminally ill cancer patients. The presence of cancer in the lungs, anxiety, and maximal inspiratory pressure are correlates of the intensity of dyspnea.

- <sup>13</sup> Okuyama T, Tanaka K, Akechi T, et al. Fatigue in ambulatory patients with advanced lung cancer: prevalence, correlated factors, and screening. *J Pain Symptom Manage*. 2001;22(1):554-564. [PMID: 11516597](#). [Full Text](#)

The purpose of this study was to clarify fatigue prevalence and the factors correlated with fatigue, and to develop a screening method for fatigue in patients with advanced lung cancer. Logistic regression analysis demonstrated that symptoms of dyspnea on walking, appetite loss, and depression were significant correlated factors. Both Cancer Fatigue Scale (CFS) and Fatigue Numerical Scale (FNS) were found to have sufficient sensitivity and specificity for use as a screening tool.

- <sup>14</sup> Stone P, Hardy J, Broadley K, Tookman AJ, Kurowska A, A'Hern R. Fatigue in advanced cancer: a prospective controlled cross-sectional study. *Br J Cancer*. 1999;79(9-10):1479-1486. [PMID: 10188894](#). [Full Text](#)

The aim of this study was to determine the prevalence of fatigue among palliative care inpatients in comparison with a control group of age and sex-matched volunteers without cancer. In addition, the correlates of fatigue were investigated. A multivariate analysis found that fatigue severity was significantly associated with pain and dyspnea scores in the patients, and with the symptoms of anxiety and depression in the controls.

- <sup>15</sup> Meyer HA, Sinnott C, Seed PT. Depressive symptoms in advanced cancer. Part 2. Depression over time; the role of the palliative care professional. *Palliat Med*. 2003;17(7):604-607. [PMID: 14594151](#). [Full Text](#)

To survey changes in depressive symptoms over time in patients with advanced cancer, and explore how effective Palliative Care Professionals (PCPs) are at assessing this, 45 advanced cancer patients were followed monthly for up to six interviews. Change in depressive symptoms over time was related to mortality; patients with marked deterioration in mood dying earlier.

- <sup>16</sup> Herndon JE 2nd, Fleishman S, Kornblith AB, Kosty M, Green MR, Holland J. Is quality of life predictive of the survival of patients with advanced nonsmall cell lung carcinoma? *Cancer*. 1999;85(2):333-340. [PMID: 10023700](#). [Full Text](#)

To confirm recent reports of the importance of quality of life (QOL) in predicting the survival of patients with lung carcinoma, the relationship between survival and QOL was examined within a group of 206 patients with advanced nonsmall cell lung carcinoma treated in a randomized clinical trial. This study did not confirm the prognostic importance of overall QOL. Rather, after adjustment for significant clinical factors, a patient-provided pain report had the greatest prognostic importance.

- <sup>17</sup> Shadbolt B, Barresi J, Craft P. Self-rated health as a predictor of survival among patients with advanced cancer. *J Clin Oncol*. 2002;20(10):2514-2519. [PMID: 12011130](#). [Full Text](#)

The relative importance of self-rated health (SRH) in predicting the survival of ambulatory patients with advanced cancer is examined. SRH was compared to clinical assessments of performance status, as well as to quality-of-life measures, using a prospective cohort design. SRH was the strongest predictor of survival from baseline.

- <sup>18</sup> Luoma ML, Hakamies-Blomqvist L, Sjostrom J, et al. Prognostic value of quality of life scores for time to progression (TTP) and overall survival time (OS) in advanced breast cancer. *Eur J Cancer*. 2003;39(10):1370-1376. [PMID: 12826039](#). [Full Text](#)

To investigate whether baseline quality of life (QoL) and changes in QoL scores from baseline are prognostic for time to progression (TTP) and/or overall survival (OS) in patients with advanced breast cancer receiving chemotherapy, QoL was assessed at baseline and before each treatment. World Health Organization performance status was significantly predictive for OS. In the multivariate analysis, more severe pain at baseline was predictive for a shorter OS. Neither baseline QoL nor QoL change scores from baseline predict OS or TTP.

- <sup>19</sup> Maisey NR, Norman A, Watson M, Allen MJ, Hill ME, Cunningham D. Baseline quality of life predicts survival in patients with advanced colorectal cancer. *Eur J Cancer*. 2002;38(10):1351-1357. [PMID: 12091066](#). [Full Text](#)

The aim of this study was to investigate the influence of baseline quality of life (QoL) on survival in patients with advanced colorectal cancer enrolled in four randomized clinical trials. Other than cognitive functioning, fatigue, appetite, constipation, diarrhea and financial domains, all QoL scales were significant independent predictors of survival ( $P < 0.035$ ). In the final model, the global QoL score remained highly significant as an independent predictor of survival ( $P < 0.0001$ ).

- <sup>20</sup> Passik SD, Dugan W, McDonald MV, Rosenfeld B, Theobald DE, Edgerton S. Oncologists' recognition of depression in their patients with cancer. *J Clin Oncol*. 1998;16(4):1594-1600. [PMID: 9552071](#).

This study was performed as part of a large depression screening project in cancer patients to determine the degree of physician recognition of levels of depressive symptoms in cancer patients and to describe patient characteristics that influence the accuracy of physician perception of depressive symptoms. Physicians' perceptions of depressive symptoms in their patients are correlated with patient's ratings, but there is a marked tendency to underestimate the level of depressive symptoms in patients who are more depressed. Physicians' ratings of their patients' distress symptoms seem to be global in nature and assessment might be improved if they probed for the more reliable cognitive symptoms such as anhedonia, guilt, suicidal thinking, and hopelessness.

- <sup>21</sup> Lloyd-Williams M, Spiller J, Ward J. Which depression screening tools should be used in palliative care? *Palliat Med*. 2003;17(1):40-43. [PMID: 12597464](#). [Full Text](#)

The present study was carried out on behalf of the Association of Palliative Medicine, Science Committee, to assess the available evidence for using screening tools for depression in palliative care. The single question 'Are you depressed?' was the tool with the highest sensitivity and specificity and positive predictive value.

- <sup>22</sup> Williams JW, Jr., Mulrow CD, Kroenke K, et al. Case-finding for depression in primary care: a randomized trial. *Am J Med*. 1999;106(1):36-43. [PMID: 10320115](#). [Full Text](#)

This randomized study conducted at three university-affiliated and one community-based medical clinics randomly assigned patients to be asked a single question about mood, to fill out the 20-item Center for Epidemiologic Studies Depression Screen, or to usual care. A simple question about depression was found to have similar performance characteristics to a longer 20-item questionnaire and was more feasible because of its brevity.

- <sup>23</sup> Block SD. Assessing and managing depression in the terminally ill patient. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians - American Society of Internal Medicine. *Ann Intern Med*. 2000;132(3):209-218. [PMID: 10651602](#). [Full Text](#)

This paper reviews the clinical characteristics of normal grief and clinical depression and explains strategies for differential diagnosis in terminally ill patients.

- <sup>24</sup> Clark D. 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958-1967. *Soc Sci Med*. 1999;49(6):727-736. [PMID: 10459885](#). [Full Text](#)

This paper expands our understanding of pain by incorporating ideas about meaning, embodiment and culture through a specific case study of the early writings of Cicely Saunders. The formulation of the concept of 'total pain', including physical, psychological, social, emotional and spiritual elements, is discussed.

- <sup>25</sup> Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med*. 1982;306(11):639-645. [PMID: 7057823](#).

This article offers a description of the nature and causes of suffering in patients undergoing medical treatment. A distinction based on clinical observations is made between suffering and physical distress. The relief of suffering and the cure of disease are seen as twin obligations of a medical profession that is truly dedicated to the care of the sick.

- <sup>26</sup> Frankl VE. *Man's Search For Meaning*. New York: Washington Square Press; 1984.

- <sup>27</sup> Bascom PB, Tolle SW. Responding to requests for physician-assisted suicide: "These are uncharted waters for both of us..." *JAMA*. 2002;288(1):91-98. [PMID: 12090867](#). [Full Text](#)

A patient with advanced amyotrophic lateral sclerosis (ALS) who requested PAS is described to illustrate the importance of physicians' willingness to explore what motivates a patient to make this request.

- <sup>28</sup> Finucane TE. Care of patients nearing death: another view. *J Am Geriatr Soc*. 2002;50(3):551-553. [PMID: 11943055](#). [Full Text](#)

This paper offers perspective and suggestions to the companions/advocates of persons with advanced, progressive, ultimately fatal illnesses and multifaceted suffering.

- <sup>29</sup> Quill TE, Byock IR. Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians-American Society of Internal Medicine. *Ann Intern Med*. 2000;132(5):408-414. [PMID: 10691593](#). [Full Text](#)

This paper presents terminal sedation and voluntary refusal of hydration and nutrition as potential last resorts that can be used to address the needs of patients with intractable terminal suffering. This paper defines the two practices, distinguishes them from more standard palliative care interventions and from physician-assisted suicide, illustrates them with real clinical scenarios, provides potential guidelines and practicalities, and explores their moral and legal status.

- <sup>30</sup> Stanley KJ. Silence is not golden: conversations with the dying. *Clin J Oncol Nurs*. 2000;4(1):34-40. [PMID: 10865582](#).

Conversations about dying involve interaction on multiple intellectual and emotional levels. The attributes that allow clinicians to function as existential messengers and communicate effectively with the dying include recognition of and confidence in one's own strengths, limits, and capabilities; clarity in one's personal understanding of living and dying; the ability to listen carefully and learn from the experience; the willingness to remain present in the face of profound anguish; and a strong belief in the worth of the work.

- <sup>31</sup> Krakauer EL, Penson RT, Truog RD, King LA, Chabner BA, Lynch TJ, Jr. Sedation for intractable distress of a dying patient: acute palliative care and the principle of double effect. *Oncologist*. 2000;5(1):53-62. [PMID: 10706650](#).

The case of a young man dying of recurrent epithelioid hemangioendothelioma, distressed with stridor and severe pain, whose poorly controlled symptoms were successfully treated with an infusion of propofol, titrated to provide effective comfort in the last few hours of the patient's life is discussed at a multidisciplinary conference. The tenet of double effect, which allows aggressive treatment of suffering in spite of foreseeable but unintended consequences, is reviewed. The patient's parents were invited and contributed to the discussion, providing compelling testimony to the power of the presence of clinicians at the time of death and the importance of open communication about difficult ethical issues.

- <sup>32</sup> Cancer care during the last phase of life. *J Clin Oncol*. 1998;16(5):1986-1996. [PMID: 9586919](#).

The American Society of Clinical Oncology (ASCO) presents its beliefs regarding the oncologists' responsibility to care for their patients in a continuum that extends from the moment of diagnosis throughout the course of the illness. In addition to appropriate anticancer treatment, this includes symptom control and psychosocial support during all phases of care, including those during the last phase of life. In this Executive Summary, ASCO identifies obstacles that hinder delivery of high-quality end-of-life care and offers recommendations for improvements.

- <sup>33</sup> Arnold EM. Factors that influence consideration of hastening death among people with life threatening illnesses. *Health & Social Work*. 2004;29(1):17-26. [PMID: 15024915](#).

This paper reviews multiple studies concerning factors that correlate with patient requests for hastened death.

- <sup>34</sup> Byock IR. The nature of suffering and the nature of opportunity at the end of life. *Clin Geriatr Med*. 1996;12(2):237-252. [PMID: 8799345](#).

This article explores the personal experience of suffering in the context of life-limiting illness. The concept of personhood is used to illuminate the nature of suffering. The concept of personhood and observed model of life-long human development is applied to the explication of the paradox of heightened sense of well being and life limiting illness.

- <sup>35</sup> Byock I, Caplan, A., Snyder, L. Beyond Symptom Management: Physician Roles and Responsibility in Palliative Care. In: Snyder L, Quill, T., ed. *Physician's Guide to End-of-Life Care*. Philadelphia: American College of Physicians - American Society of Internal Medicine; 2001:56-71.