

The Request for Assistance in Dying

The Need for Psychiatric Consultation

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Background. Public initiatives and legislative proposals have increased the likelihood that some states will legalize euthanasia and assisted suicide as a means of ending the suffering of patients with terminal illness. However, suggested safeguards that would guide physicians in such cases have not properly addressed the need to evaluate psychosocial factors that could motivate patients' requests for premature death.

Methods. Four cases of patients with cancer who expressed a wish to end their lives prematurely are described. These cases were evaluated with regard to mental and emotional functioning.

Results. Pain and suffering, organic mental disease, depression, and personality issues play significant roles in patients' requests for assistance in dying.

Conclusion. Comprehensive psychosocial assessment is needed when evaluating requests for assistance in dying. This assessment may reveal hidden problems or conflicts that affect rational decision making, a prerequisite to informed consent for any procedure or intervention. *Cancer* 1993; 72:2786-91.

Key words: psychosocial, assistance in dying, consultation.

In recent years, the courts, the medical profession, and the public have struggled with dilemmas surrounding continued medical care for patients who are hopelessly ill and incompetent. Such well-publicized cases as Karen Ann Quinlan and Nancy Cruzan have called attention to the fact that medical technology can prolong survival in a vegetative state without awareness or abil-

ity to participate in human interaction. Many have argued that this is not life at all and have supported judicial rulings and legislation to provide for the use of advanced directives, the removal of life support in incompetent patients who have little hope of recovery, and the withholding of treatment when it would not benefit the patient.

Although there is a consensus that relief of suffering by discontinuing medical treatment in the patient with a terminal illness is an acceptable goal of patient care, a debate ensues as to whether physicians should assist actively in the death of their patients and whether persons have a right to die at a time of their choosing. The viewpoint that persons have a right to die has been popularized by organizations such as the Hemlock Society. The recently published book *The Final Exit* by the Society's founder, Derek Humphry, details the means by which persons can take their own lives.¹ This book rose to the top of the *New York Times* best-seller list in the self-help category the first week after its publication, demonstrating a widespread desire for information on this issue. Many people, especially the elderly, believe that the process of dying can be more terrible than death itself and euthanasia or assisted suicide can provide death with dignity. In a recent poll, 53% of the respondents agreed that physicians should be legally allowed to perform euthanasia.² This past year, initiatives in the states of Washington and California to permit euthanasia in cases of terminal illness were defeated narrowly. Several legislatures are now considering laws favorable to this effort.

Although some physicians have privately admitted to have secretly helped their patients with terminal illnesses to prematurely end their lives,³ open discussion of this issue has been accelerated by several well-publicized cases in which physicians have assisted patients in ending their lives.⁴⁻⁷

The position of practicing physicians on the issue of assisted suicide and euthanasia, however, is difficult to

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Accepted for publication May 21, 1993.

determine. In a 1988 poll of California physicians, 70% of the respondents believed that patients should have the option of requesting active euthanasia when faced with an incurable illness, and another 45% said they would participate in carrying out the patient's request.⁸ A poll of physicians in the state of Washington, however, indicated that 60% opposed legalizing the use of a lethal dose of medication to end a person's life and 75% were not willing to participate in assisted death.⁹

The perception that it may be only a matter of time before States enact euthanasia legislation has led to a call for guidelines and procedural safeguards¹⁰⁻¹² that would establish standards to be met before assistance in dying could be provided. Quill, for example, proposed five clinical criteria for physician assistance in dying: (1) that the patient have an incurable condition associated with severe, unrelenting suffering; (2) that the patient's suffering and request not be the result of inadequate comfort care; (3) that the patient's choice be made clearly, repeatedly, and freely; (4) that the patient's judgment not be distorted; and (5) that assisted death be performed only in the context of a meaningful physician-patient relationship.¹²

These criteria, although important, do not address completely the complexity of the clinical situation and the effect of psychosocial factors on rational decision making, a prerequisite to informed consent. Below we illustrate the importance of comprehensive psychosocial assessment in addressing requests for assistance in dying by showing how several different mental and emotional problems can lead to feelings of hopelessness and a desire to end one's life. The cases described are of patients with cancer consulted by the Psychosocial Medicine Service at the H. Lee Moffitt Cancer Center, Tampa, Florida, but we believe that the principles are applicable to other persons with terminal illnesses.

Affective Disorders

Case 1

A 67-year-old woman was admitted to the Moffitt Cancer Center for progressive lower extremity weakness. She had received a diagnosis 6 years previously of multiple myeloma, and nephrotic syndrome and amyloidosis had developed recently. Although the patient was ambulatory when she entered the hospital, her weakness worsened, confining her to bed. A computed axial tomography scan demonstrated spinal cord compression. When the prognosis was conveyed to her, she became demoralized and talked of suicide. A psychiatry consultation was requested by the attending physician. The evaluation described the patient as an intelligent, well-spoken woman with a strong German accent.

During the interview, she stated that she could no longer take care of even her most basic needs and expressed a wish to die and a desire for discharge. On a subsequent interview, she asked the psychiatrist for help in ending her life. Her mood was depressed and her affect sad. She was tearful at times during the interview, especially when she discussed her limited physical abilities. The patient was told by the consulting psychiatrist that she had depression secondary to the rapid onset of physical disability and that this was particularly severe because of the value she placed on being autonomous. He said he believed her sense of hopelessness was being worsened by the depression and that antidepressant medication and psychotherapy might help her feel better. She agreed to a trial of methylphenidate, which was later switched to fluoxetine. She was seen daily by the psychiatrist and was able to discuss her feelings of helplessness. Her mood improved and she did not speak further of suicide.

Comment

Patients with terminal illnesses may express sadness because of their situation, but most usually do not wish to die prematurely. Both Brown and Chochinov, in their separate studies of patients with terminal illness, showed that a wish for death was more likely to be associated with a diagnosis of major depression.^{13,14} Major depression is often associated with a pervasive loss of self-esteem and feelings of worthlessness and uselessness. Patients with depression may also be more likely to desire early death because they believe they are a burden to others. Major depression is often difficult to diagnosis in the patients with terminal illness, because cachexia, medication, and other factors related to the disease can mimic the apathy and withdrawal associated with depression. Moreover, the diagnostic criteria for depression rely on the endorsement of physical complaints common to both depression and serious illness. Depression in patients with terminal illness, therefore, is probably overdiagnosed^{15,16} and mistakenly believed by many physicians to be a normal part of the dying process.¹⁷ Terminally ill patients with major depression may respond to antidepressant medication, especially psychostimulants such as methylphenidate and dextroamphetamine.^{18,19} These may also promote appetite and decrease apathy, dysphoric mood, and withdrawal associated with the anorexia-cachexia syndrome.

Unrelieved Symptoms

Case 2

A 52-year-old married woman underwent surgery for breast cancer 1 year previously. She did well for a time

but developed painful metastases to the ribs, vertebra, and base of skull and was receiving radiation therapy. This failed to relieve her pain sufficiently. In addition, because of the family's confusion and denial about the seriousness of her disease and her highly independent personality, she was receiving little support at home. When her pain became severe, she did not complain to family members. She was referred for psychiatric consultation because when she arrived for a radiation therapy appointment, she talked of killing herself. The patient appeared agitated and distressed and said she had withdrawn \$500 from the bank and was on her way to buy a gun after her treatment because she was unable to endure the pain and resulting depression. At the psychiatrist's suggestion, she was evaluated by the palliative care team. They initiated a regimen of slow-release and intermediate-release morphine, which provided adequate pain control. When seen by the psychiatrist again, she appeared more relaxed and less desperate. A meeting was arranged with the family and patient to assist them in coping with the illness. Through family therapy, they were able to discuss their fears about her illness and negotiate ways to allow the patient to accept help while maintaining activities important to her autonomy. She no longer spoke of killing herself.

Comment

An important source of anxiety for the patient with terminal illness is that efforts to relieve suffering due to pain and other symptoms will fail.¹⁷ This is especially true for patients with malignant disease; moderate to severe pain occurs in an estimated 60–90% of patients with advanced cancer.²⁰ As many as 25% of patients are thought to die without adequate pain relief.²¹ Saltzberg, in a study of 185 cancer patients with pain, found that 17% had suicidal ideation.²² Although suicidal thoughts alone do not justify a diagnosis of major depression, patients with cancer who experience pain are more likely than those without pain to have psychiatric disturbances, including depression, anxiety, hostility, and hypochondriasis. Pain, anxiety, and uncontrolled symptoms often cause sleep disturbance, which adds to patient's suffering by increasing fatigue, hopelessness, and irritability. Public surveys show a great deal of anxiety and apprehension about cancer pain. In one survey, 69% of respondents stated that they would consider committing suicide if their cancer pain got bad,²³ and in the previously cited survey of California physicians, persistent pain and symptoms were identified as the primary reason for patients requesting assisted suicide.⁸ In our experience, however, patients are often reluctant to report pain because they fear the side effects of medication or are mistakenly concerned about becoming ad-

dicted. Furthermore, many physicians do not routinely ask patients about pain and may undermedicate patients because of misplaced fears about addiction. This is unfortunate, because, most patients can experience pain relief with current treatments. Foley suggested that the number of patient requests for assisted suicide in Holland, where the practice is tolerated, might be lower if there were better access to hospice care.²⁴

Personality and Psychodynamic Issues

Case 3

A 48-year-old woman was referred for psychiatric evaluation because of anxiety about her disease. She had recently undergone wide excision of an infiltrating ductal breast carcinoma with axillary lymph node dissection. She came to the Moffitt Cancer Center seeking a second opinion, and it was recommended that she receive radiation and adjuvant chemotherapy. On evaluation, she was an attractive, well-dressed, and meticulously groomed woman. Her history was remarkable for bilateral breast augmentation and cosmetic facial surgery. She believed in nontraditional medicine and took vitamin C and selenium to augment her immune system. During the psychiatric interview, she expressed distress over the possibility of cancer recurrence and the potential loss of her attractiveness. She was also upset about the possible side effects of chemotherapy, especially hair loss. She stated that when she was a young woman she had witnessed the confinement of a brother in a convalescent home for rheumatic fever and was terrified of becoming debilitated. She returned for a follow-up appointment several days later. She told the psychiatrist that she had obtained a formula for killing herself from the Hemlock Society and requested a prescription for the medications, which she wanted to use if she had a recurrence. This request was declined, and continued follow-up counseling was suggested. She did not keep subsequent appointments. She eventually underwent radiation therapy and remains disease-free 2 years later. We do not know if she obtained the medications she requested.

Comment

According to Lipowski, illness may represent a threat, loss, or challenge or may even bring a sense of relief.²⁵ Thus, some persons will struggle to persevere in the face of suffering. For others, the psychological demands of illness can be more daunting than the physical ones, and they may have great difficulty tolerating the uncertainty, helplessness, and loss of control that accompanies illness. Also, treatment requires collaborative deci-

sion making with the medical team and the ability to endure the frustration of physical discomfort, postponed tests, and hospital confinement. Persons with certain personality characteristics may find these tasks overwhelming. In the case presented above, narcissistic or histrionic traits are manifested by an overinvestment in appearance and body integrity. Clinically, the threat of hair loss, disfiguring surgery, or changes in physical appearance can be manifested by depressed mood, somatization, or feelings of humiliation.

In several other situations, requests for assisted suicide may also represent the unfolding of complicated personality interactions: the compulsive person who requires organization, predictability, and routine and feels angry because his or her life is now out of control; the chronically dependent personality whose low self-esteem results in a feeling that he or she is a burden to others; and the omnipotent person who derives a sense of mastery over life by being able to determine exactly how and when he or she will die.²⁶

In the above examples, the request for assistance in dying does not necessarily emanate from a rationally thought-out process. Instead, it can be seen as a protest against the demand to adapt to living on terms different from one's own or even as a plea for help in resolving long-standing conflicts.

Organic Mental Disorders

Case 4

A 65-year-old man was admitted to the hospital with graft versus host disease. Forty-three days previously, he had undergone a bone marrow transplant for chronic myelocytic leukemia. His graft versus host disease was characterized by a severe skin rash, hematuria, neutropenia, oral candidiasis, herpetic infection, and abnormal results on liver function tests. Six days after admission, he told a staff nurse, "I just want to die. Is there something you can give me to kill me?" Psychiatric evaluation showed an alert but somewhat uncooperative man with impaired attention and poor eye contact. His mood was angry. He was oriented to city, state, and hospital, but he appeared to be experiencing visual hallucinations and his speech was slow and showed some looseness of associations. He had difficulty responding to commands. An electroencephalogram demonstrated a pattern characteristic of encephalopathy. This was thought to be secondary to his underlying disease and his multiple medications, which were impairing cognitive functioning.

Comment

The prevalence of delirium in hospitalized general medical patients can approach 30%.²⁷ In studies of patients

with cancer, prevalence has ranged from 10% to 85%, with the higher number found in the population with terminal illness.²⁸ Delirium is characterized by cognitive impairments that include misperception of the environment, faulty information processing, difficulties in retention and retrieval of information, and deficient insight and judgment. Delirium can be caused by direct involvement of the nervous system by disease (less common) or by indirect metabolic and toxic factors related to disease or its treatment (more common). Cancer treatments that can cause delirium include narcotics, anticholinergic agents, and some drugs used for chemotherapy, especially steroids. Delirium may increase a patient's sense of helplessness. Hallucinations that may accompany delirium can be frightening and be interpreted by the patient as evidence of becoming insane. Delirium often causes a lowering of inhibitions and the emergence of primitive coping reactions. During this time, delirious patients may express ideas and thoughts they would normally repress. Although patients in a severely confused state may be unable to carry out self-destructive acts, patients with mild delirium may be at increased risk for killing themselves. Delirium was found to be a diagnosis in as many as 20% of suicidal patients with cancer or acquired immunodeficiency syndrome.²⁹ Delirium may wax and wane and is often diurnal, so that a patient who is thinking clearly in the morning may be confused in the afternoon. Correctly diagnosing delirium rests on demonstration of cognitive deficits on mental status exam or through the presence of visuomotor deficits.

Discussion

If laws to allow assistance in dying are passed either through referendum or legislative action, there will be patient requests and physicians to assist. Up until now, the effort to legalize assistance in dying has not been supported by professional organizations that would be directly or indirectly involved. These include the American Medical Association, which is concerned through its Council on Judicial Affairs, with ethical standards for practice; the American Bar Association; and the American Hospice Association. Thus, little debate has ensued concerning how such laws would be implemented. As several authors have pointed out, to prevent assistance in dying from being abused, guidelines similar to those used in Holland will need to be implemented.^{9,11} In that country, euthanasia, although still illegal, is not prosecuted in the case of patients with terminal illness, providing that (1) the request is voluntary and thoughtful, (2) no other solution to the patient's suffering can be found, and (3) a second opinion is obtained to ensure that guidelines have been met.

Although these guidelines are useful, we believe that there has been inadequate emphasis on psychosocial evaluation.

First, if assistance in dying is provided to patients, then a determination of the patient's competency to give informed consent is essential. This would ensure that a patient's choice is free from coercion and would determine that the patient has the medical capacity to agree to assistance in dying. The latter determination, made by physicians, is also referred to as clinical competency.

Proposed guidelines for determining medical capacity have been published.³⁰⁻³² At a minimum, the competent patient must (1) be able to express a choice, (2) demonstrate a factual understanding of the situation, (3) appreciate the significance of the facts presented, and (4) be able to weigh the facts rationally. Although there may be some disagreement as to how strictly these criteria should be applied, a general rule is that the greater the risk of the procedure, the more stringently the criteria are applied.

Most who write on the subject of aid in dying identify depression as the problem that concerns them most in deciding the competency of the patient.^{10,16,33-36} This seems appropriate because, as we have shown, depression in a very ill person is often difficult to diagnose. However, as illustrated by the case examples presented in the current study, emotional problems other than depression can affect a patient's attitude, understanding, reasoning, and, ultimately, ability to provide informed consent. Moreover, these problems often go undetected in the persons who are ill.^{37,38} We therefore recommend an expanded psychosocial assessment that would determine the presence or absence of psychiatric problems such as those discussed previously. However, it would also evaluate the rationality or irrationality of the patient's choice, because the presence of emotional problems does not necessarily preclude the ability to give informed consent. Battin proposed an interview procedure that is useful in this regard. It explores, among other things, the purpose of the request, its stability and consistency with the patient's basic values, whether the suicide plan is financially motivated, the effect of the suicide on others, the person's fear of becoming a burden to others, and alternatives to suicide.³⁹

Second, we are concerned that the process of providing psychosocial assessments may be thwarted by legal concerns. In this age of medical malpractice litigation, it is hard to imagine that hospitals would allow patients to be assisted in dying without a judicial ruling on competency to protect them hospitals against wrongful death suits. The result might be to prolong patient suffering until this is obtained or dictate that

most assistance in dying would be provided to patients in their homes, where psychiatric assessment or even a second opinion would less likely be available. This may encourage physicians to violate safeguards and guidelines, as in the Dutch experience, where most aid in dying is provided at home, and 25% of physicians admitted to assisting patients with dying without collegial consultation.⁴⁰

Last, the psychosocial evaluation of patients who request assistance in dying will present a considerable challenge. Sorting out the complex interaction between medical, mental, and other factors in patient requests can be difficult. Psychiatrists, therefore, would appear to be the best equipped to make such an evaluation. However, psychiatrists are traditionally trained to prevent suicides. They often treat patients without terminal illness who suffer greatly from physical and mental illness, such as those with multiple sclerosis, chronic obstructive pulmonary disease, or intractable schizophrenia. Thus, there is a bias toward helping patients find a way to cope with their suffering, and those psychiatrists evaluating patients with terminal illness will need to strive to maintain their objectivity, neither prejudging a patient's request for assistance in dying as irrational, nor yielding to the temptation to overidentify with the patient's suffering.

Neither of the recent referenda in the states of Washington and California mandated psychiatric assessment in their proposals. We believe, however, that psychosocial assessment should not be optional and that all patients requesting assistance in dying require a careful, objective, and expert evaluation, which those working closely to the patient are usually unable to provide. Although the involvement of a consultant who may peer into the personal life of the patient may at times meet with resistance, it provides a safeguard against a precipitous request by a patient in the midst of emotional trauma or suffering from an undetected psychiatric disorder. In some cases, patients may be helped by management of their symptoms or assistance with finding an acceptable alternative to hastened dying. In other cases, however, a patient's desires may be rational, well thought-out, and consistent with his or her value system. Once a patient has been assured of assistance in dying, the urgency of a request may be diminished because the patient knows that control can be obtained over the time and place of death.

Providing assistance to dying patients is illegal and therefore reported rarely. Thus, there has been little discussion of the effect of emotional problems on patient decision making. If laws are enacted to allow assistance in dying, however, they will force us to implement guidelines and examine this issue more closely.

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